Ideologies and Outcomes in Temporomandibular Disorders

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This thesis is dedicated to the memory of Douglas Charles Durham and S.L.P.

It is a testimony to Doug's principle of P.M.A.

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Abstract

Temporomandibular disorders (TMD) are a group of relatively common chronic disorders that often result in pain affecting the face, specifically the temporomandibular joint and associated muscles. Treatment strategies are varied, with only a minimal evidence base. The psychosocial aspects of TMD are generally recognised to be important and complex.

The aim of this thesis is to understand the philosophies of care that underpin the professional management of TMD, and to explore the patients' experiences of their illness and its management. The ultimate purpose is to use this information to target future interventions at specific points in the care pathway.

Qualitative studies of professionals' and individuals' experiences of managing and living with TMD were undertaken. In depth interviews were conducted with eighteen professionals and twenty-nine individuals suffering from TMD. The data were then analysed and used to develop a map illustrating the patients' journey through care.

The results exposed the large variation in clinical practice and considerable professional uncertainty about optimum management. Patients' experiences reflected the professional uncertainty, and some of the psychosocial effects experienced on the journey through care appeared to have an impact on outcome. The uncertainty over diagnosis in primary care led to a lack of

legitimisation of the sufferer's complaint, which had concomitant effects on their day-to-day functioning. This, in turn, perpetuated any psychological distress they might already be experiencing.

In conclusion, this thesis highlights the experiential basis of TMD management, and the underlying ideology of, "do no harm". In primary care the sufferers experience a lack of legitimacy in their complaint due, in part, to a lack of a diagnosis. There is a need for a targeted programme of education in primary care in the diagnosis and management of TMD. This might reduce the level of uncertainty and concomitant psychosocial effects that sufferers experience currently.

1 Introduction

Temporomandibular disorders (TMD) are managed in a variety of ways, some efficacious, some not (McNeill, 1997). One of the key reasons for the variation in practice is the deficiency of good quality evidence to base practice upon (Marbach and Raphael, 1997). This has been attributed to the lack of a valid and reproducible outcome measure for TMD (Al-Ani et al., 2004; Koh and Robinson, 2003; Shi et al., 2003). This thesis contributes to a much larger project run by a research team within the School of Dental Sciences that seeks to address this problem and develop a TMD patient-based outcome measure specific for TMD. There are four key phases to this wider project:

1) Determination of an appropriate review and reference period for an outcome measure specific for TMD
2) Item by item case-control analysis of an available measure of oral health related quality of life (Oral Health Impact Profile 49 [OHIP 49] (Slade and Spencer, 1994b)) to develop a preliminary tool suitable for use as a measure of outcome in TMD.
3) Ascertainment of new items that may be required for the modified measure
4) Validation of the prototype measure.

The work described in the thesis is contributing to the third phase of the project but also draws on data from phase one and is providing some data for phase two. Much of the work for in the larger project is completed with the exception of the final selection of items for the prototype measure and its final validation.

Although data from this thesis are contributing to the development of the measure, the main body of this work has a different, complementary, purpose as described in the aims and objectives. Within this thesis there are three sets of qualitative data from three separate but linked studies. The studies are:

1. Reported management of TMD and rationale behind it (Study A) - Professional interviews.
2. Discernment of the reference and review period (Study B) – Patient interviews.
3. Exploration of patient's map through care (Study C) – Patient interviews.

Studies A and B were run simultaneously and their analysis informed study C.

I carried out all of study A and its data were used in three ways:

- It gave invaluable insight into the reasoning behind treatments used in TMD also helping to give context to the wider project by investigating professional definitions of success.
- It helped inform the topic guide for the second stage patient interviews (Study C).
- The results from this study were compared with the patient perspective (Studies B & C).

The first part of study B was conducted by another PhD student (Moufti, 2007) with the primary aim of discerning the reference and review periods for TMD. During its analysis a nascent theme emerged from the data that modified

study C in this thesis. I then completely reanalysed data from study B from uncoded transcripts to examine the emergent theme and started to develop theory from the data. Data from study B will be used later in the thesis to illustrate how the theory was developed further in study C.

My original plan had been to identify potential new items for the outcome measure project. It soon became apparent that the data from study A (professionals) and the emergent theory from study B required a great deal of further work to understand the psychosocial consequences of TMD for the sufferer and how this affected their journey through care.

The nature of the data collected from study C meant that it was possible to use it to contribute to the wider outcome measure project but this is not detailed in the main body of this thesis. Nevertheless, a section detailing this work is included in the appendix for information (Appendix 4, Section 8.4).

This thesis gives a greater understanding of the problems the healthcare profession experiences in relation to TMD and the psychosocial consequences of the illness for the sufferer. The interrelated nature of the professional and patient interpretations of the condition has never been examined before. The data this thesis provides will hopefully go some way to helping inform and target interventions; interventions that both address the problems the profession experiences and the psychosocial consequences the sufferers report

2 Literature Review

2.1 Introduction

There are three distinct areas of literature that I intend to review. These are the literature pertaining to:

1. Temporomandibular Disorders (TMD)
2. Chronic illness
3. Clinical decision-making

They are all important in the explanation of TMD, its management and its psychosocial effects. As they are three distinctly separate areas each will have its own conclusion.

2.2 Temporomandibular disorders

2.2.1 Temporomandibular disorders and their signs and symptoms

Temporomandibular disorders (TMD) are a collection of disorders that can affect the muscles that move the jaw (muscles of mastication), the jaw (the Temporomandibular joint) or both. TMD can present as pain in and around the jaw region, clicking or crepitus of the joint, or locking of the joint where the individual affected may only be able to open 15-20mm ("closed" lock/disc displacement without reduction) or may not be able to close their mouth ("open" lock/dislocation of the joint). The pain maybe situated in or radiate to: the muscles of mastication, of which there are some in the neck and temple as well as the face; the joint, which is situated in front of the ear; or the ear, due to its close proximity to the joint.

Signs and symptoms of TMD were first recognised by Costen in 1934 (Costen, 1934). He attributed these to occlusal disharmony (problems with the way the teeth meet together) in particular overclosure and included symptoms such as impaired hearing and oropharyngeal burning sensations alongside the more classical symptoms of pain in the joint and surrounding musculature. Costen's syndrome, as TMD was then known, was subject to a number of criticisms and probably represented oversimplification of an amalgam of different orofacial pain conditions.

Shore (Shore, 1959) in the 1950s coined the term "Temporomandibular joint dysfunction syndrome" and described the condition again in relation to occlusal disturbance. It was not until the 1980s that recognition of the multifaceted nature of TMD caused Bell (Bell, 1982) to use the phrase by which the collective of conditions are now known. The American Association of Orofacial Pain defines TMD as:

"A collective term embracing a number of clinical problems that involve the masticatory musculature, the Temporomandibular joint and associated structures, or both. They [TMD] are considered to be a sub classification of musculoskeletal disorders". (McNeill, 1990)

This definition reflects increasing appreciation of the varied nature of TMD and professional uncertainty about its aetiology.

Signs and symptoms of TMD are present in 20-75% of the population and 2-4% of the population present for treatment. The age of presentation is between 20-40 years of age and the female to male ratio is 1:1 for symptoms but females outnumber males in presenting for management, 7:1 (de Bont et al., 1997; De Kanter et al., 1992, 1993; Gray et al., 1994; Von Korff et al., 1988). Suggestions that this is due differences in gender behaviour are frequent in the literature but are not scientifically supported (de Bont et al., 1997).

Signs and symptoms of TMD are clinically variable and often idiosyncratic but they include six broad groups (Gray et al., 1994; McNeill, 1997; Suvinen et al., 2005; Turk, 1997):

- Joint noises – clicking, creptius (grinding)
- Locking – open (dislocation) closed (inability to open fully)
- Pain – in head, neck and shoulders
- Muscular tenderness – in face, neck and shoulders
- Ear complaints – otalgia, tinnitus etc.
- Psychosocial effects

Out of this group only joint clicking has been found to be significantly associated with continued TMD symptoms on follow-up after twenty years (Carlsson et al., 2002).

The recognition of the wider impact of TMD, its variability in expression and its mainly benign self-limiting course when managed conservatively (de Leeuw et al., 1994; Magnusson et al., 2000; Stohler, 1997) led to acknowledgement of it as a chronic illness (Dworkin and Massoth, 1994). This move has helped progress treatment philosophies a little, with new more innovative management techniques aimed not solely at its symptomatology but also at its psychosocial effects.

2.2.2 Aetiology of TMD

The aetiology of TMD is poorly understood and frequently misrepresented.

There are initiating factors, predisposing factors and perpetuating factors and consequently no single "cause". When the term multifactorial is used in relation to the aetiology of TMD, it is used as a colloquialism and tends to refer to all three factors (Mew, 1997). Okeson (Okeson, 2003) identifies five factors associated with TMD: occlusal factors, trauma, emotional stress, deep pain input and parafunctional activities, but these have been the subject of much debate and zealous treatment (Alanen, 2002; Auerbach et al., 2001; Ciancaglini et al., 2001; Dao and Lavigne, 1998; De Boever et al., 2000a, b; John et al., 2002b, 2003; Kirveskari and Alanen, 2000; Lobbezoo and Lavigne, 1997; Macfarlane et al., 2001; Mongini et al., 2000).

McNeill (McNeill, 1997) in his review of TMD concepts and controversies suggested that initiating factors in TMD are related to trauma or repetitive adverse loading of the TMJ and its musculature. He went on to link parafunction, hormonal factors and psychosocial factors with perpetuation of the illness. The science involved, and the political implications of the aetiology make it difficult to obtain professional consensus over the nature of the aetiology. In terms of the science, TMD is difficult to attribute to initiating factors due to its biopsychosocial fluctuating nature which allows for a great deal of interaction between factors (Le Resche, 1997).

There are many vested interests; especially clinicians who seek to prove their own management techniques work. The result of this is that the literature is punctuated with confusing messages about the role of occlusion, stress, depression and the need for surgery in TMD (Greene et al., 1998). This serves only to complicate matters for the rest of the medical world and particularly the primary care practitioner who is usually the first point of contact for the patients affected.

Occlusal therapy and occlusion is discussed in more depth in section 2.2.5, but it is relevant here to briefly discuss the role of posterior tooth loss that some suggest is a significant aetiological factor in TMD (Agerberg and Carlsson, 1973; Budtz-Jorgensen et al., 1985; Helkimo, 1976; Scholte et al., 1993). More recent research using more powerful data sets and analyses has failed to demonstrate a significant link between tooth loss and TMD (Abraido-Lanza, 2004; Bibb et al., 1995; Carlsson et al., 2003; Ciancaglini et al., 1999). The consensus that appears to be forming within the literature is that occlusal variables are not the primary aetiological factor in TMD and that the replacement of missing teeth should only be carried out "on prosthodontic indications after reversible treatment has alleviated pain and dysfunction" (De Boever et al., 2000a; Suvinen et al., 2005).

It is likely that aetiological theories that combine the biomedical and psychosocial aspects of TMD are more appropriate (Mew, 1997) and a

number of authors have proposed a biopsychosocial explanation as the way forward (Laskin et al., 2006; Suvinen et al., 2005).

2.2.3 Diagnosis of TMD

Diagnosis of TMD depends on the history, the clinical examination and special tests (Mohl and Ohrbach, 1992). However, as Mohl and Orhbach point out, our scientific knowledge to diagnose TMD is poor due to the scarcity of good quality evidence. Lund et al (Lund et al., 1995) define special tests that can be used in the diagnosis of TMD as predictive, screening, discriminatory or monitoring.

Predictive tests are not available for TMD at present (Lund et al., 1995) due to the uncertainty over its aetiology. Screening tests may include such epidemiological indices as the Helkimo index (Helkimo, 1974a, b, c), the TMJ scale (Levitt and Lundeen, 1987; Levitt et al., 1988) and the Craniomandibular index (CMI) (Fricton and Schiffman, 1986, 1987). All three aim to screen populations for the presence of signs and symptoms of global TMD. None of them seek to sub classify the patient in any way. None of the Helkimo index, TMJ scale or the CMI are routinely used as clinical diagnostic tools (discriminatory tests) due to their inability to distinguish between different sub-groups of TMD. Lund et al (Lund et al., 1995) assert that this is also due to clinicians' desire to use a system that provides an "intuitively and easily explainable diagnosis".

Simple plain radiography, despite much debate, has not been found to be particularly useful in the diagnosis or monitoring of TMD (Crow et al., 2005; de Bont et al., 1993; de Leeuw et al., 1993, 1995; Dijkstra et al., 1995; Emshoff et al., 2003; Epstein et al., 2001; Limchaichana et al., 2007; Melis et al., 2007; Ohnuki et al., 2006; Pullinger and White, 1995; Raustia et al., 1994; Westesson, 1993; White and Pullinger, 1995; Widmalm et al., 2006). It is, however, useful for demonstrating, or excluding, other pathology of the Temporomandibular joint with Computed Tomography (CT) being limited to the same use. Magnetic resonance imaging (MRI) has been accepted as the current gold standard for imaging of the joint and its associated structures when the history and clinical exam indicate (Laskin et al., 2006) although it is not without problems such as false positives (Ohnuki et al., 2006; Okeson, 2003) and misinterpretation (Widmalm et al., 2006). It is only really useful in cases where there is internal derangement of the joint structure or function. Other newer imaging techniques, such as ultrasound (Melis et al., 2007), have yet to undergo thorough evaluation.

Other tests such as jaw tracking, vibratography, sonography, electromyography and thermography have been suggested as screening, discriminatory and monitoring tests over the years. Only one, thermography has received any real backing and this is on the basis that it has still not been fully investigated. The others have been rejected as unreliable in all potential functions as tests (Lund et al., 1989, 1995; Mohl et al., 1990a, b, c).

The final option available is a clinical diagnostic index. There have been a number of attempts over the years to construct a definitive index (Bell, 1982; Dworkin and LeResche, 1992; Eversole and Machado, 1985; Farrar, 1972; Laskin and Block, 1986; McNeill, 1990; Truelove et al., 1992). The common problems with the early diagnostic systems were either: too much focus on derangement (Farrar, 1972); a lack of inclusion or exclusion criteria or clarity of distinction between diagnosis (Bell, 1982; Eversole and Machado, 1985; Farrar, 1972); they did not permit multiple diagnoses (Eversole and Machado, 1985; Farrar, 1972) and provided limited information on standardising the examination process (Bell, 1982; Eversole and Machado, 1985; Farrar, 1972). Bell's classification (Bell, 1982) of TMD did, however, simplify the multitude of terms available and started the move towards distinguishing myogenous conditions from those with some form of internal derangement.

The National Institute of Dental Research in the U.S.A. supported research into producing clinically applicable research criteria for TMD. The result of this sponsorship was the Research Diagnostic Criteria (RDC) (Dworkin and LeResche, 1992) a dual axis approach to the diagnosis of TMD. Axis 1 concentrates on the clinical examination and the Axis 2 concentrates on the psychosocial effects of the condition. The RDC has a standardised protocol for examination, permits multiple diagnoses and has well defined inclusion and exclusion criteria. It is, however, extremely long therefore prohibiting its routine day-to-day clinical use in all but its simplest classification (Axis I physical findings).

The RDC is the only empirical, operationally based diagnostic system, that is, it diagnoses from clinical examination only. Its three Axis I groups of TMD are: Group I – Myofascial Pain Disorder; Group II – Disc Displacement Disorder; Group III – Degenerative disease disorder. It has shown fair to good reliability in diagnosing into these distinct sub-groups (John et al., 2005; Lausten et al., 2004) but when pain was not required for a diagnosis for example disc displacement without reduction its reliability decreased (John et al., 2005). This is probably due to the fact that clicks and crepitus can be difficult to elicit reliably and that TMD signs and symptoms can fluctuate widely. The RDC is, however, reliable enough to be the only descriptive diagnostic system in wide spread use for TMD research.

2.2.4 Psychological and psychosocial factors in TMD

The psychosocial aspects of TMD began to be recognised through the work of Laszlo Schwatrz and colleagues in the 1950s (Schwartz, 1956). They began to concentrate more on the mental constitution of patients rather than their occlusal relationships. Laskin and Greene then carried on this work through from the 1960's (Laskin, 1969) to the current day (Greene and Laskin, 2000). TMD is now recognised as a biopsychosocial illnesses; a trio of physical, psychological and psychosocial factors (Suvinen et al., 2005). These have measurable impacts of TMD on oral health related quality of life (Reissmann et al., 2007) but the relationship between these impacts and the affects on the patient, is best described as indirect and complex (Ohrbach and Dworkin, 1998). There is still no real evidence to equate any aspect of psychology as an aetiological factor, or as a consequence of TMD. Irrespective of this, the influence of psychological factors on TMD is of therapeutic importance (Suvinen et al., 2005).

It is known that psychological disorders are prevalent in patients suffering from TMD (Gatchel et al., 1996; Parker et al., 1993); that they increase the risk of progressing to long-term TMD, which is difficult to manage (Wright et al., 2004), and that their role varies depending on gender (Phillips et al., 2001). Specifically, the presence of psychological disorders is more frequent in females, in the form of depression (Phillips et al., 2001).

Psychological disorders are present in both acute and chronic TMD patients but more so in the latter and it is thought that they may have an influence on the progression towards chronic TMD (Gatchel et al., 1996). It is known that the myofascial sub group of TMD (Group I in RDC Axis I) have a predisposition to experiencing more psychological distress than the other sub groups (McCreary et al., 1991). This is keeping with Reissman et al's (Reissmann et al., 2007) finding that this group experience the greatest impact on their oral health related quality of life.

A taxonomy of TMD sufferers based on their psychological characteristics has been derived (Rudy et al., 1989). It characterises sufferers as dysfunctional, interpersonally distressed or as adaptive copers, somewhat defamatory terms and possibly relevant only at a clinical level. The dysfunctional individual has higher levels of pain causing greater life interference and psychological distress. The interpersonally distressed individual feels that their family and friends are not supportive of them and their condition. The adaptive coper has lower levels of pain severity and less interference in their daily activities. They also feel they have greater levels of control and higher levels of daily activity. They appear more able than the other two groups to manage their TMD successfully.

This taxonomy has been supported by further similar work (Suvinen et al., 1997) and has been investigated in relation to treatment outcome (Rudy et al., 1995). In terms of treatment outcome, the dysfunctional and interpersonally

distressed individuals obtained greater reductions in pain intensity than the adaptive copers. This, however, is probably a result of the fact that these two groups had greater problems to start with and another study has found the dysfunctional profile to be associated with treatment failure (Dahlstrom et al., 1997).

The terms used by Rudy et al in their classification (Rudy et al 1989) could be considered prejudicial towards those demonstrating high levels of psychological disturbance. Rudy et al's work triggered a body of research that examined TMD patients using primarily psychological indices (Auerbach et al., 2001; Forssell et al., 2005; Jerjes et al., 2007; Lindroth et al., 2002; Wright et al., 2004; Yap et al., 2002). Patients with TMD demonstrate psychological complaints but the scientific community must be careful not to label patients suffering from this chronic illness as purely psychological cases. The wider effects of TMD must not be forgotten; the types of psychological measures that have become somewhat commonplace within TMD research cannot always capture these. The wider effects are probably more appropriately assessed through the use of quality of life measures (Section 2.2.6). This also avoids stigmatising patients through the use of "pure" psychological indices.

Two of the more common psychological disorders in chronic TMD are somatization (55% of patients) (Garofalo et al., 1998; Gatchel et al., 1996; Yap et al., 2002) and depression (39% of patients) (Meldolesi et al., 2000; Yap et al., 2002); this is in keeping with chronic pain generally (Birket-Smith, 2001). Both somatization and depression are felt to affect treatment

adversely, with patients being less able to cope and placing greater demands on healthcare (Dworkin, 1994; Fricton and Dubner, 1995; Yap et al., 2002) (Wright et al., 2004).

Somatization has been defined as consisting of three components: the predilection to report non-specific physical symptoms; an inclination to seek medical management; and emotional disturbance (Dworkin, 1994). In TMD it is significantly associated with the development of chronic TMD, which is difficult to manage (McCreary et al., 1992; Wright et al., 2004).

Somatization has been found in many chronic conditions such as lower back pain, fibromyalgia and irritable bowel syndrome. Wessely et al (Wessely et al., 1999) argue for a broader view of these types of condition. They suggest that the multiple functional somatic syndromes are one entity and the specialist clinicians managing them are like a “blind man feeling different parts of the same animal”.

Indeed some of the conditions such as fibromyalgia and lower back pain are often found as co-morbidities to TMD (Balasubramaniam et al., 2007). They also share similar symptoms: sleep difficulties, headache, muscular pain, joint pain and also have a tendency to become chronic fluctuating illnesses (Fantoni et al., 2007). The advantage to regrouping all these types of somatic illnesses under one classification is that idiosyncratic management might decrease and broad evidence based biopsychosocial management might then become more the norm.

The affective disturbance in TMD often involves depression and or anxiety (Gatchel et al., 1996; Kafas and Leeson, 2006; Rollman and Gillespie, 2000; Wright et al., 2004; Yap et al., 2002). Depression has been associated with TMD for a number of years (Auerbach et al., 2001; Madland et al., 2000; Tversky et al., 1991; Vimpari et al., 1995) and there has been much debate about its role in chronic pain conditions such as TMD (Fishbain et al., 1997). This debate centres around whether the depression is an antecedent or a consequence (diathesis stress model) of the pain. In a familial study with TMD sufferers Dohrenwend et al (Dohrenwend et al., 1999) found support for the diathesis stress model and felt that depression is a consequence of TMD. This would seem to be intuitively true, as if the person is experiencing large amounts of poorly controlled pain they may well become depressed about it.

Anxiety and depression are both felt to encourage catastrophisation and passive coping (Madland et al., 2000), which do not assist adaptation to TMD. The adaptation to chronic illness and TMD is covered further in Section 2.3.3. The negative effects of anxiety and depression are borne out by TMD patients who exhibit high levels of depression and anxiety as they commonly progress to chronic TMD (Garofalo et al., 1998; Gatchel et al., 1996; Wright et al., 2004).

All of the psychological factors detailed can affect pain beliefs, coping and adaptation to TMD. Further discussion of this can be found in Section 2.3.3.

2.2.5 Management of TMD

The literature surrounding the management of TMD is vast, often confusing, idiosyncratic and largely scientifically unsubstantiated. This is in the main due to methodological flaws, the multitude of outcome measures employed (Okeson, 2003), the lack of a reliable standardised measure so that meta-analysis of randomised controlled trials can occur (Al-Ani et al., 2004; Koh and Robinson, 2003) and until recently (1992), the lack of a clear classification of TMD for research purposes. This paucity of evidence has led to a consensus that reversible conservative therapy, because of its efficacy in relieving symptoms, should be the first-line management for TMD (Dimitroulis, 1998; Greene and Laskin, 1974, 1983; McNeill, 1997). It should be instituted once organic pathology such as systemic disease, hereditary conditions or neoplasia are excluded as a possibility.

In 1996 the National Institute of Health (NIH) in the U.S.A. called for reversible conservative therapy as the primary treatment modality in TMD unless organic pathology was present (Albino, 1996). They defined conservative therapy as including: supportive patient education, physical therapy (physiotherapy), pharmacological pain control, intraoral appliances and simple occlusal therapy.

The other, irreversible, therapies purported for TMD are complex occlusal interventions (such as full rehabilitation) and surgical approaches (Albino, 1996). There are, of course, less "medical" therapies available for TMD,

somewhat derisively named as unconventional therapies (Greene, 1995a). These include transcutaneous electrical nerve stimulation, soft laser, radiofrequency surgical cauterization and chiropractic care. None of these, according to Greene, has any scientific foundation to be recommended as a treatment modality in TMD.

Conservative therapy

Studies utilising conservative therapy as previously defined by the NIH have reported success rates of 68.2% to 95% (Carraro and Caffesse, 1978; Greene and Laskin, 1974, 1983; Magnusson and Carlsson, 1983; Nel, 1978; Randolph et al., 1990; Sato et al., 1997). All of these studies used differing outcome measures. Interestingly, the study reporting a 68.2% success rate undertook no active treatment with patients suffering from TMD diagnosed as anterior disc displacement without reduction (Sato et al., 1997). This suggests that there is a natural remission for some types of TMD and also raises the question of placebo effects occurring with conservative therapy. The placebo effect of therapy for TMD was investigated in a series of trials by Greene and Laskin's team at the University of Illinois. They found that they could elicit a 35-60% placebo response rate through their trials (Goodman et al., 1976; Greene and Laskin, 1971, 1972, 1974; Laskin and Greene, 1972; Shipman et al., 1974).

Greene and Laskin discuss this placebo effect and the power of doctor-patient interaction in their review of TMD (Greene and Laskin, 2000) and conclude, "with TMD patients it is often not what is done for them, but how it is done,

that is important". In other words, whatever is planned may best be planned in a biopsychosocial context.

A number of approaches have been used within conservative therapy: cognitive behavioural therapy, physical therapy, pharmacological therapy, and intra-oral appliances. Although cognitive behavioural therapy has been used with varying success in TMD patients (Dworkin, 1997) it is suggested that all patients might experience some benefit from it (Turner et al., 2007). It aims to increase patients' knowledge about factors that influence TMD symptoms; increase functional and physical activities; and train individuals to use relaxation, hypnosis and other techniques to modify the perception of pain and related sensations (Dworkin et al., 1994).

Physical therapy (physiotherapy) seems an intuitive choice for an individual who may have pain in their musculature. Its aim is to restore normal joint function, decrease loading and pain and facilitate rehabilitation to normal everyday activities (Di Fabio, 1998). Unfortunately as most reviews have illustrated, physical therapy, although it produces short-term relief of signs and symptoms, has little evidence suggesting that it produces a long-term reduction in signs and symptoms of TMD (Chapman, 1991; Feine and Lund, 1997; Feine et al., 1997; Michelotti et al., 2005; Sturdivant and Fricton, 1991).

Pharmacological therapy for TMD has utilised such classes of drugs as Non Steroidal Anti-inflammatories (NSAIDS), Opiates, Anti-depressants, Anxiolytics and Corticosteroids. As Dionne (Dionne, 1997) points out, in his

review of pharmacological interventions for TMD, most of those pharmacological agents used to manage TMD have not completed any standardised assessment of efficacy. They often, therefore, fall into the category of unvalidated clinical practice.

NSAIDS are recurrently used for such inflammatory musculoskeletal conditions as Rheumatoid arthritis and would seem to be indicated, by association, for TMD. They have only modest support in the scientific literature (Dionne, 1997; Laskin et al., 2006). Their effects are difficult to separate from placebo effects in myogenous TMD (Singer and Dionne, 1997). Some new generation NSAIDS have, however, been shown to be somewhat more effective (Ta and Dionne, 2004) in management of the pain of disc-displacement with reduction.

Opiates as an analgesic measure are rarely used for TMD. This is due to the high incidence of adverse effects and dependence, and the lack of trials utilising them with TMD (Dionne, 1997; Laskin et al., 2006). Tricyclic antidepressants and anxiolytics (the benzodiazepines), however, are two of the more thoroughly investigated pharmacological modalities utilised in TMD (Dionne, 1997) but their evidence base still has its limitations (List et al., 2003). Their usage is often justified through evidence that they are effective in chronic orofacial pain rather than in TMD specifically. Anxiolytics and Tricyclic antidepressants have both been shown to be efficacious in TMD, particularly with patients with myogenous TMD and clinical symptoms of depression

(Dellemijn and Fields, 1994; Harkins et al., 1991; Pettengill and Reisner-Keller, 1997; Plesh et al., 2000; Singer and Dionne, 1997).

Intra-articular and systemic corticosteroids are no longer commonly used in TMD with the exception of the arthritides (Okeson, 2003). Corticosteroids' short-term intra-articular efficacy in helping relieve symptoms of rheumatoid arthritis in the TMJ has been demonstrated (Kopp et al., 1991). Their use in TMD, however, is debatable (Laskin et al., 2006; Shi et al., 2003).

The final approach to conservative management is the use of intra-oral appliances. Many designs of intra-oral appliances have been purported as efficacious in the management of TMD and I will limit my review to the two most common, the soft splint and the stabilisation splint (Lindfors et al., 2006; Pierce et al., 1995). The soft splint is usually a flexible polyvinyl, 2mm thick, full coverage "mouth guard" type lower jaw appliance (Gray and Davies, 2001). It is not adjusted to the occlusion but it will provide approximate bilateral occlusal contact.

The stabilisation splint can be provided in either jaw but more frequently is provided in the upper jaw (maxillary). Usually it is constructed from hard acrylic or from softer polyvinyl, or a combination although these are less common approaches (Wright, 2005). It is adjusted to the patient's occlusion quite accurately and provides an optimal occlusion for the individual which places their condyles in their most "musculoskeletally stable position" (Okeson, 2003).

The mechanism of action of splints is poorly understood and disputed, with physiological and behavioural mechanisms the main theories mooted (Dao and Lavigne, 1998). Splints' effectiveness is also a matter for debate due to: variation in outcome measures; variability in follow-up; and explanation of treatment outcomes (Major and Nebbe, 1997).

Stabilisation splints have their proponents (Davies and Gray, 1997; Forssell et al., 1999; Magnusson et al., 2004) and opponents (Marbach and Raphael, 1997; Turp et al., 2004) too. The literature behind them is also varied, for many of the reasons previously detailed throughout this chapter. Their efficacy, as with so many TMD treatments, may also be questionable as there is some evidence to show the "placebo" effect is similar to their own (Wassell et al., 2004). However, it must be questioned whether a non-occluding splint really is a placebo. A systematic review of stabilisation splints usage (Al-Ani et al., 2004) recently concluded that there was insufficient evidence to argue for or against their widespread usage and therefore they continue to be used, most commonly for myogenous and arthogenous TMD (Wassell et al., 2004). They can also be used as a diagnostic aid to see if occlusal therapy is indicated.

Soft splints are widely used for initial management in the UK but have little evidence to support their efficacy. In myogenous TMD they appear to significantly improve symptoms in comparison to no intervention (Wright et al., 1995) and perform as well as stabilisation appliances (Pettengill et al., 1998).

As with stabilisation splints there are, however, counter claims that they are ineffective (Nevarro et al., 1985; Okeson, 1987) and some say that they can cause increases in symptomatology in a small number of sufferers (10% of sufferers, (Gray and Davies, 2001). These claims and counter-claims are all somewhat flawed due to the methods used in the studies investigating, and the 10% claimed by Gray and Davies appears unsubstantiated by any evidence. As they are, however, inexpensive, easy to construct, well tolerated by most patients and possibly efficacious, they probably should and still will be, used by most general dental practitioners as the initial management of choice for TMD sufferers.

Irreversible therapy

The two main forms of irreversible therapy for TMD, occlusal therapy and surgery, have over the years, had periods of quiescence and periods of fervent usage. They have also, over the years, developed passionate proponents, especially occlusal therapy. As has been found throughout the TMD literature irreversible therapy has supporting and detracting evidence, for the same endemic reasons as the inconsistent evidence for conservative therapies.

Occlusal therapy's inception was with Costen's original syndrome (Costen, 1934) where he questioned the "bite" of individuals presenting with signs and symptoms of TMD and suggested that treatment ought to be directed towards correcting it. In particular, correcting overclosure due to loss of teeth or worn

dentures. Subsequently, the ideal occlusion of teeth became somewhat of a mantra and prophylactic measures to correct it became briefly acceptable (Molin, 1999). The theory underlying the correction of occlusion was that it, to a large extent, controlled the forces applied to the TMJ and muscles of mastication and therefore if it were optimum there would be no TMD.

The process of equally distributing contacting forces across the teeth and "correcting" the occlusion is known as equilibration and it is done through a complex process of a diagnostic stabilisation splint, sometimes mounted study model trials (a mock equilibration) and eventual grinding of the teeth in the mouth (the occlusal equilibration).

Occlusal therapy has been shown to be effective in some cases (Forssell et al., 1986, 1987; Vallon et al., 1991, 1995) but evidence for its widespread use as prophylaxis or treatment has found to be lacking (Forssell et al., 1999; Koh and Robinson, 2003; Tsukiyama et al., 2001). The best summation of its use is by De Boever et al (De Boever et al., 2000b) in their review, "Occlusal therapy and occlusal adjustment as the only treatment modality is rarely defendable; however, in combination with other forms of therapy, occlusal adjustment can contribute to a positive treatment outcome in selected cases".

The other irreversible therapy for TMD is surgery. It has evolved over the years as theories on the aetiology of TMD have changed. As Greene and Laskin began to report the psychological input into TMD in the 1960s its popularity and use began to wane (Dimitroulis, 2005). Its use increased again

in the 1970s with minimally invasive "closed" techniques such as arthroscopy coming more to the fore, helping explain the molecular pathology of TMD (Dolwick, 1997). This low morbidity, minimally invasive, out-patient procedure allowed lysis and lavage within the joint cavity helping, it is claimed, to reduce signs and symptoms of arthrogenous and disc displacement TMD (McCain et al., 1992).

In the current era, surgeons generally aim to stay out of the joint space due to the problems experienced with derangement of disc function and infections in the past. If the joint space is to be entered, minimally invasive procedures such as arthrocentesis or arthroscopy (Dolwick and Dimitroulis, 1994; Dolwick, 1997) are used to try to reduce the likelihood of any complications. In the main, most surgical procedures will involve arthrocentesis or arthroscopy, which both have reasonable evidence supporting their efficacy and safety (Laskin et al., 2006).

2.2.6 Determining success in TMD treatment/trials

There is a lack of a standardised reliable outcome measure in TMD. Trials have used multiple, non-standardised outcome measures making meta-analysis very difficult (Al-Ani et al., 2004; Koh and Robinson, 2003). The more common objective measures used are: measurement of inter-incisal opening; measurement of lateral and protrusive jaw movements; and assessment of pain levels. The more subjective ones include: questioning the patient about their level of improvement; resolution of joint noises; and muscular/joint palpation for tenderness. In the past, measurements such as

electromyographic changes, bite force, sonography, vibratography and jaw tracking have been tried but have largely now been discredited (Laskin et al., 2006).

The reliability of the objective measures is reasonable with inter-incisal opening unassisted pain free having an intra-class correlation of 0.9 and assisted painful opening one of 0.96 amongst trained observers (Dworkin et al., 1988). The reliability of measuring lateral and protrusive excursions, however, is slightly lower at 0.7, which is probably a result of a poorly defined end-point for the examiner measuring it. The more subjective measurements of muscular tenderness and joint noise have relatively low kappa coefficients[1] and are less reliable (0.6 for muscular palpation and 0.61 for joint noise) (Dworkin et al., 1988).

Measuring the patient's pain is fraught with difficulties. Pain is a subjective, emotional individual experience and can be modified by a number of factors; this makes it inherently difficult to measure simply (Katz and Melzack, 1999). Simple unidimensional measurements such as visual analogue and descriptive scales have been trialled with TMD by LeResche et al (Le Resche et al., 1988) and Conti et al (Conti et al., 2001). LeResche et al found the reliability of visual analogue and visual descriptive scales to be very poor. Conti et al found them to be relatively sensitive (30-50%) but, all bar the numerical scale, displayed a decrease over a period of time where no treatment had been initiated thereby showing their imprecision for the

[1] >0.75 excellent, 0.75-0.6 good, 0.6-0.4 acceptable

complex nature of TMD. Unidimensional pain scales also do not account for the other more wide-reaching effects of pain and can be modified, as Conti et al point out, simply by reassurance from the health professional.

The more reliable and thorough forms of pain measurement are the multidimensional approaches such as the Multidimensional Pain Inventory (Kerns et al., 1985), which has been used in classifying TMD patients (Rudy et al., 1989) and been shown to help predict treatment response (Dahlstrom et al., 1997; Rudy et al., 1995). It is, therefore, likely to be sensitive enough to capture some of the change in patients undergoing treatment for TMD. The fluctuating and unpredictable nature of TMD pain, however, makes any outcome based wholly on the assessment of current pain doubtful; measurement of pain would need to be maintained over a period of time while the complaint of the sufferer may not be wholly about the pain!

Clearly, there are a number of possible approaches to measuring outcome in TMD and all are problematic in some way. The reasons include:

1. With several of the approaches the tests are often insufficiently sensitive or specific. In other words you may measure something that does not relate strongly or unequivocally to TMD (Dworkin et al., 1990; Okeson, 2003)
2. Without blinding, the risk of bias for measures based on clinical examination is very high (Dworkin and LeResche, 1992)
3. None of the measures account for all biopsychosocial outcomes.

Measuring the impact of TMD

In recent years oral-health related quality of life measures have started to be used in TMD patients. The first indication that quality of life measures might be sensitive to the biopsychosocial effects of TMD came through the work of Reisine et al (Reisine and Weber, 1989; Reisine et al., 1989). These two studies showed that quality of life measures: recorded the impact of TMD on the individual; were sensitive to differences between TMD patients and other patients; were sensitive to change over time with treatment.

A range of oral health related quality of life measures have been designed in the last two decades since Reisine et al's work. Most of the work with TMD has been done with the Oral Health Impact Profile (OHIP) (John et al., 2002a, 2007; Larsson et al., 2004; Murray et al., 1996; Segu et al., 2005), although the Medical outcomes Study (Di Fabio, 1998) and the Child-health questionnaire-child form 87 (CHQ_CF87) (Jedel et al., 2007) have also been used but these are not oral-specific. All of the research has shown measurable difference between quality of life in TMD patients and controls and some studies have also demonstrated measurable change in quality of life with management of TMD (Di Fabio, 1998; Jedel et al., 2007; John et al., 2002a, 2007; Larsson et al., 2004; Murray et al., 1996; Segu et al., 2005).

The sensitivity of OHIP to TMD's effects is a promising development as it utilises a generic model of oral health (Locker, 1988) that seems well suited to capture TMD's impact on quality of life. There is however work to be done before OHIP can be used as a TMD outcome measure. The key areas that

would need investigating are its: validity, reliability, responsiveness to change and cross-cultural behaviour in TMD. In broad terms it needs to be: valid, it measures what it pertains to measure; reliable, it consistently measures the same time and time again; responsive to change, it will indicate the degree of change in the quality of life if it worsens or improves. In addition to this it must be fit for purpose; it is practical to apply it in the situation it is to be used in and intelligible to those subjected to it and those who apply it. It may therefore need adaptation from its 49-item version.

In terms of its general validity and reliability, OHIP in its unaltered form is a well tested oral health quality of life measure (Robinson et al., 2003; Slade and Spencer, 1994a, b; Slade, 1997) based on a generic model of oral health (Locker, 1988). Despite this model of oral health being based on a previous World Health Organisation model of health (WHO, 1980) it is still comparable to the new International Classification of Functioning, Disability and Health (WHO, 2002). OHIP has been validated both in the U.K. (Robinson et al., 2003) and many other countries (Fernandes et al., 2006; Ide et al., 2006; John et al., 2002a; Larsson et al., 2004; Pires et al., 2006; Slade and Spencer, 1994b; Wong et al., 2002) and it undoubtedly measures oral health related quality of life. Cross-cultural issues have been examined by a number of studies and although some differences have been identified, OHIP would appear to be relevant to most populations (Allison et al., 1999; Steele et al., 2004).

Generic (non-oral) quality of life measures such as Short-form 36 (SF 36) have been found to be less able to discriminate between groups of patients with disparate dental conditions than oral health related quality of life measures, specifically OHIP (Allen et al., 1999). Versions of OHIP are now available that are specific for clinical diagnoses or situations, for example edentulous patients; this helps with their specificity and clinical applicability (Allen and Locker, 2002). Allen et al (Allen and Locker, 2002) demonstrated similar validity and effect sizes for their modified short version of OHIP for edentulous patients to both the 49 item (Slade and Spencer, 1994b) and 14 item (Slade, 1997) versions of OHIP. To form a TMD specific version of OHIP a similar process to Allen et al's study would have to be undertaken to ensure validity, reliability and responsiveness to change.

Responsiveness to change for oral health related quality of life measures has been discussed in depth (Locker, 1998) and the scoring of OHIP, when used as an outcome measure, has also been examined (Allen et al., 2001; Slade, 1998). Any oral health related quality of life measure would need to be able to measure change effectively.

2.2.7 Conclusion

The management of TMD suffers greatly due to the lack of a good quality evidence base for interventions. This is, in the main, due to difficulties with diagnosis and the lack of a reproducible outcome measure, although the former is now less of a problem since the advent of the RDC. TMD is now recognised as a biopsychosocial condition with wide-ranging effects. This status as a chronic illness, however, has not brought new and alternate management modalities; one exception is cognitive behavioural therapy. Further scrutiny of the chronic illness literature might help progress the management of TMD.

2.3 Chronic illness

2.3.1 Background

Seventeen and a half million people in the U.K. report a chronic illness (DoH, 2005a). This translates to 6 out of 10 adults in the household population suffering from a chronic illness accounting for 5% of in-patient bed days, 42% of all acute bed days, and 80% of consultations with general practitioners (Wilson et al., 2005).

2.3.2 Introduction

Most Temporomandibular disorders can be considered as a chronic illness (Dworkin and Massoth, 1994). The term "chronic illness" is best suited to the variety of long-term medical complaints that patients can suffer from (Dowrick et al., 2005). This is due to the fact that there is no need for a discernable pathophysiological process. Three broad kinds of chronic illness are defined (May, 2005):

1. Those characterised by multiple and complex co-morbidities – for example, diabetes, angina pectoris
2. Those characterised by "biomechanical incapacity" - for example the arthritides and fibromyalagia
3. Those characterised by psychosocial experiences – for example severe depression, anxiety and chronic pain

These categories, as May points out, are not mutually exclusive and TMD falls into both the second and third categories. Most kinds of chronic illness will,

though, have a predominant characteristic and all of them will have some biopsychosocial effect.

Most TMD belongs to the chronic pain group of chronic illnesses (Dworkin et al., 1992; Madland et al., 2001) and some have called for a diagnostic subclassification of chronic orofacial pain to be created within this (Madland et al., 2001) to aid clarity and management. Pain itself is defined as an "unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of tissue damage" (IASP, 2007). Chronic pain, defined by the same organisation, is said to be one that lasts greater than six months after onset and may have no easily definable pathology.

Why is the classification of most TMD as a chronic illness, and further sub classification as a chronic pain condition important? It allows TMD to be examined generically against the abundant chronic illness and pain literature within medicine and social science as opposed to the paucity in dentistry. This will allow greater understanding of the experiences and multiple self-regulatory processes of chronically ill patients, thereby allowing comparisons to be made with TMD. This process of comparison may, in turn, allow new treatment strategies for TMD.

2.3.3 Psychosocial impact of chronic illness

Early sociological research into illness revolved around the Doctor:Patient relationship (Parsons, 1951). A large amount of work conducted since has examined the phases and progression of chronic illness (Dworkin et al., 1992; Gullacksen and Lidbeck, 2004; Lazarus, 1992; Leventhal et al., 1992; Paterson, 2001; Salick and Auerbach, 2006; Shaul, 1995; Velez and Ramasco, 2006). The first discussion of Doctor:Patient relationship (Parsons, 1951) became known as the Parsonian "sick role". It is mainly applicable to acute illness and describes for patients two rights and two obligations. The patient's rights are: they could suspend some of their day-to-day activities because they were "sick"; they should receive help from their close family and friends in recognition of their sickness. The patient's two obligations are: to seek help from the Doctor and comply with him/her; to seek to "get well" as quickly as possible.

This seminal work occurred in the 1950s when the professional-patient relationship was greatly different from now and chronic illness was less well recognised. We now have a consumer-driven healthcare system and more chronic illnesses (DoH, 2000, 2004; RPSGB, 2003). Patients are now well aware of the flaws in medical decision-making; they only have to consult the mass media to be told about "Alderhey" and the "Bristol babies" (Dyer, 2001; Hall et al., 2001). This means that such a paternalistic and therefore prescriptive professional-patient relationship rarely happens now. Hence the submissive patient depicted in the sick role is probably not now the norm.

That said the sick role still has its merits for understanding the role illness plays in society. People with chronic illnesses still experience symptoms, for example otalgia (earache), in TMD; they still talk to relatives about it to seek suspension of some social activity to help with the experience. They will still seek medical care and the legitimacy it brings. They may not, however, accept the professional's decision that there is little that can be done. They are now empowered by the information literate age we exist in, to examine the professional's judgement and decide for themselves whether they regard it as correct or not.

The patient who refuses to accept, or questions, medical authority may, however, be seen as troublesome as they have rejected one of the obligations of the sick role (Jeffrey, 1979). The power in the social role of being sick allows the patient to be labelled by the health professional as difficult (Friedson, 1970). This labelling/typification (Bond and Bond, 1994) can result in delegitimisation of the patient's complaint in the eyes of the profession and if they continue to reject medical authority, social support from their close family and friends may also diminish.

With any chronic illness there is ongoing illness that often never really enters a fully recovered phase. Individuals are expected to obtain maximal functioning within the scope of their illness and only in acute exacerbations occupy the sick role. This ongoing symptomatology has social consequences that are summarised by Bury's concept of Biographical Disruption (Bury, 1982), but not well accounted for in the sick role. Biographical disruption

suggests that day-to-day living is in upheaval due to the chronic illness and that this upheaval places individual's "wider social networks face-to-face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support" (Bury, 1982). The stages of Biographical Disruption are characterised as: a) Insidious onset and recognition; b) Emerging disability and uncertainty and c) Mobilisation of resources.

These stages are similar to the sick role in that, the patient experiences symptoms and/or disability, seeks help and gains information, and then mobilises family and friends to support them in their social obligations. The difference is that this whole process is ongoing rather than a linear progression to an end-point. This is a result of the fact that the sick role was intended for acute illness, a fact Parsons himself recognises (Parsons, 1975). He goes on to suggest that in chronic illness there is constant movement between the sick and recovery role. This, although accounting for the fluctuant nature of chronic illness, does not really explain or account for the long-term nature of the symptoms and disability that the individual faces in relation to their day-to-day lives.

Bury's Biographical disruption attempts to clarify this ongoing biopsychosocial struggle in relation to chronic illness, albeit through the eyes of an elderly sample suffering from Rheumatoid arthritis. The degree of disruption individuals experience in their social existence, as Williams points out (Williams, 2000), is therefore very much dependent on the context, norms, age and experiences of the individual concerned. However, this ongoing

biographical disruption may make a patient deviant in respect to the sick role, especially if in the attending clinician's mind this social role is still present. They may be seen as not satisfying the obligation to get better (Parsons, 1951) as they cannot recover fully and therefore may be held responsible for their illness, especially if medicine cannot help e.g: chronic medically unexplained pain. Due to their deviancy they lack legitimacy from the medical profession for their complaint.

Legitimacy of an individual's complaint has been suggested to have three variations (Friedson, 1970). The first is that the individual is ill with an illness from which they can recover and the sick role is entered temporarily. The second is that the individual has a terminal illness and they enter the sick role with "unconditional legitimacy". The final and third variation is that the individual has a condition that can be viewed as being due to, "their own fault", or has a label of deviancy from the medical profession which makes the sick role illegitimate. These individuals still therefore have the obligations of, but don't possess the rights of, the sick role, which in the face of ongoing biographical disruption can lead to further biopsychosocial effects. Without the legitimacy of entering the sick role, the individual may be stigmatised either a) by the condition that is "their own fault" e.g. a sexually transmitted disease or b) as a malingerer or someone who has psychosomatic or stress related complaints in relation to the label of deviancy, e.g. back pain, and this can be interpreted as a stigma.

Stigma was initially proposed by Goffman (Goffman, 1963) and is defined as an "attribute, trait, or disorder that marks an individual as being unacceptably different from the "normal" people with whom he or she routinely interacts" (Scambler, 1998); it can be felt or enacted. The individual may, therefore, experience discrimination from the professional by being labelled as a malingerer, an enacted stigma. Or they may feel stigmatised as a result of "stigma coaches", such as family or work colleagues, who due to the lack of legitimisation from the medical profession implicitly suggest they are a malingerer (Scambler and Hopkins 1986).

Goffman (Goffman, 1963) divides individuals with stigma into, those who are discredited and those who are discreditable. This division is on the basis of the "visibility" of their stigma, in the former their illness is apparent to the outside world for example they may be wheelchair bound, in the latter it is not always immediately apparent, for example TMD. He goes on to assert the major differences between these two groups are in their "Impression management" and "Information control". Those who are in the discredited group may need to manage the society labelling they receive and may need to try and change that opinion. Those individuals who are discreditable due to their illness have to make a decision whether or not to be open about their illness. This decision will often be made on their view of the potential stigma they have.

This is not to say that all individuals with a chronic illness will be passive and accept stigmatization, some, as Goffman acknowledges, will use it as a

motivator to change societal perceptions through political lobbying and other means (Susman, 1994). Others, however, will spend time utilising varying strategies to reach societal "acceptability". Denying or hiding the existence of chronic illness can affect the patient's adaptation to it.

The discreditation in chronic illness may therefore, be due to: an individual's perceived failure to fulfil the obligations of the sick role; society's rejection of the complaint as an illness; a lack of diagnosis and legitimacy of the complaint; or the stigma of the complaint. In any case, the consequences of the discreditation can be far reaching, as Charmaz's discussion of the "loss of self" describes (Charmaz, 1983). She suggests that the suffering of chronic illnesses can involve: discreditation; social isolation; restriction of day-to-day activities; and burdening of others. These four, she suggests, result in a loss of self; your inner consciousness of your identity. This generally means the individual loses their positive perspective on their original pre-illness identity.

The culmination of this loss of self is the possibility that the individual concerned constructs a new negative introspective self based upon their social isolation, restriction, discreditation and burdensome-ness gained from interactions/reactions from others. They then may not rebuild a new, valid, positive self due to the ongoing chronic process, the suffering endured due to the illness and the continued discreditation of stigma, or deviancy from the sick role. They will only tend to rebuild a new positive self if they adapt to, or are shown methods to help them adapt to, their illness.

Individuals may or may not experience biographical disruption, stigmatisation and or loss of self. To a large extent whether or not they do depends on their adaptation[2] to the illness, which depends sometimes on clinical input. Two main models of adaptation, applicable to chronic illness, have been suggested. Taylor (Taylor, 1983) suggested a Cognitive Adaptation model that involves three main processes:

1) Search for meaning
2) Mastery of illness
3) Restore self esteem

The individual's search for meaning involves defining the illness they suffer from and understanding its long-term implications. This initial phase allows adjustment to the illness' social implications, a process similar to biographical disruption. Once sufferers establish meaning, they seek to gain mastery of their illness (coping), gain symptomatic control of their illness thereby allowing for as little disruption to their day-to-day existence as possible. If they establish any degree of mastery they can then restore some self-esteem; this is done through reconstruction of their personal (outward) identity by trying to minimise the effects the illness might have on their personal identity, the inverse of loss of self.

The second model of adaptation involves the suggestion that stress and coping play a role in adapting or adjusting to chronic illness (Lazarus and Folkman, 1984; Lazarus, 1992), the Transactional model of stress and coping (Lazarus and Folkman, 1984). There are three distinct phases to this model.

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[2] the process of making changes in order to adjust constructively to life's circumstances

The first, Primary Appraisal, involves the individual making a judgement on whether an event or symptom is stressful or not. If it is, a second process occurs, Secondary appraisal, whereby the individual examines their possible actions (coping strategies) in the face of this stressor and their likely success. The third stage of implementing these coping strategies, coping itself, then occurs.

As part of a process of reappraisal, applicable to both models, Williams (Williams, 1984) suggests that patients try and construct their own meaning of the illness by attributing its genesis to an event in their life; he terms this "narrative reconstruction". In his interviews with elderly Rheumatoid Arthritis sufferers he found that asking the question "why do you think you got arthritis?" resulted in them trying to link arthritis to varying causative situations or agents. These were not necessarily identical to medical models of the aetiology of their condition but did often bear similarities to them. He contends that patients require this narrative reconstruction because of the lack of a medical answer and therefore they need a bridge to understanding "why me?" By doing this, as well as explaining the onset, patients may be seeking to put a positive "spin" on the illness in relation to its effects or their religious beliefs, again perhaps as part of a process of reconstructing a new positive self.

Both models of adaptation (Lazarus and Folkman, 1984; Taylor, 1983) have similarities and it is outwith the remit of this review to discuss them in depth. Their core concept of coping, which is central to adaptation, is however, relevant to this review, but what is coping? Three terms, that have often been

misused, in relation to patient adaptation to chronic illness have been very clearly defined (Bury, 1991). "Coping" itself is where the individual develops tolerance to the effects of his/her illness, for example mild aching in muscles of mastication after a meal. "Strategies" are the actions the affected individuals take to minimise the effects of their illness, avoiding hard, chewy foods during an acute exacerbation of TMD. "Style" refers to the way in which people approach or respond to their illness, for instance recognising their TMD and acknowledging it rather than denying its existence or assuming a more sinister diagnosis.

Coping strategies maybe ineffective leading to the consequences proposed in Charmaz's (Charmaz 1983) "loss of self". The employment of effective coping strategies depends on the individual's psychological make-up. There have been multiple attempts to classify these strategies (Lazarus and Folkman, 1984; Rosenstiel and Keefe, 1983; Suls and Fletcher, 1985) one of the simplest being Radley's classification (Radley, 1994). This describes strategies as being either problem based or emotion based; the former concentrating on dealing with the problems of the illness and the latter the emotional impact of the illness. Problem based strategies include insulin dependent diabetics adjusting the timing of insulin administration to preserve their social life (Campbell et al., 2003) and emotion based strategies, the increase in positive activities such as recreation to minimise depression in Rheumatoid arthritis (Shaul, 1995). Specific strategies for dealing with chronic illness are well summarised by Sarafino (Sarafino, 2002).

Factors affecting adaptation to chronic illness

An individual's "successful adaptation" to a chronic illness is linked to their ability to institute efficacious coping strategies which, in turn, can be affected by a number of factors. In a review of psychological factors associated with adaptation to a chronic illness Keefe et al (Keefe et al., 2004) identified processes that helped coping (self-efficacy, readiness to change and acceptance) and those that hindered it (pain catastrophisation, helplessness and pain related fear and anxiety).

Self-efficacy describes the person's inner belief that they can manage the consequences of the illness they have. In TMD this could be the belief they could manage any acute exacerbations by conservative techniques they had been taught. Self-efficacy has largely been the driver behind the governmental proposals for the "Expert patient" (DoH, 2001). This program is targeted at encouraging self-efficacy and ensuring patients can self-manage their own chronic illnesses. Self-efficacy is therefore helpful in adopting active coping strategies towards chronic pain and it is possible for it to moderate or mediate the adaptation process (Abraido-Lanza, 2004; Brister et al., 2006; Litt et al., 2004; Schiaffmo and Revenson, 1992). Hence a large part of the self-management program for chronic illnesses is aimed at increasing self-efficacy (Lorig and Holman, 2003; Lorig, 2003) (Section 2.3.5).

Increasing self-efficacy is possible by four mechanisms (Lorig and Holman, 2003; Lorig, 2003): 1) Skills mastery; 2) Modelling; 3) Reinterpretation of symptoms; and 4) Social persuasion. Skills mastery involves the formulation

of an action plan for that week. The individual concerned makes realistic targets for management of the illness using the strategies they have been taught. The premise of skills mastery is that confidence in ability improves when one does things.

Modelling revolves around learning from others' actions. Taking the TMD example, this would mean individuals learning a new coping strategy from another individual with TMD. It can be achieved through "self help" groups and audiovisual or written material.

Reinterpretation of symptoms is similar in nature to narrative reconstruction (Williams, 1984); it is a process by which symptoms are reconstructed positively as an entity that can be addressed. For instance clicking on opening in TMD can be addressed by an understanding of how common a condition it is, but that when there is uncontrolled discomfort or noise the use of exercises or a splint can help, rather than just resting it. Reinterpretation aims to get patients to re-examine their symptoms and find strategies for coping with them.

Social persuasion is one of the more powerful mechanisms. Support from the individual's relatives can help encourage the individual into adaptive behaviours; something as simple as changing the family's meal to a less "chewy" one when the individual is undergoing an acute exacerbation of TMD can help greatly. The underlying theory is that sufferers are more likely to adopt beneficial behaviours if these are performed by others around them.

This process parallels the rights of the individual within a legitimised sick role and is undoubtedly linked to this. If, however, an individual is considered illegitimate in their claim to the sick role this persuasion will diminish and adaptation will become more difficult.

This social persuasion or social legitimacy also plays an important part in determining the individual's "readiness to change" (Prochaska and DiClemente, 1983); this is defined as the individual being in a state of mind to adapt their behaviours to help cope with an illness. To trigger a *state* of readiness to change there are five key factors (Dalton and Gottlieb, 2003). The *process* of changing is then via contemplation, preparation, action and maintenance (Prochaska and DiClemente, 1983); they consider what they need to do, prepare for it including garnering social support, and then make the changes required. The process and the maintenance of the change is very much dependent on social support and consequently, therefore, is also dependent on the legitimacy of the perceived illness. When the change is made in chronic illness it has been found to produce a more positive perspective on the predominant chronic illness and less anger and frustration about it (Dalton and Gottlieb, 2003), a process that could be suggested to be the start of a reconstruction of self.

A lack of readiness to change, "behavioural disengagement" from learning to manage their symptoms has found to be prevalent in TMD patients suffering from myofascial symptoms (Ferrando et al., 2004). The same research group in a later paper (Galdon et al., 2006) found these patients to have significantly

higher levels of psychological distress and anxiety than patients with the sub diagnosis of articular TMD[3]. Pain location in TMD, however, has not consistently proved to be a reliable indicator of psychosocial distress.

Both of the previous two factors influencing successful adaptation, self-efficacy and readiness to change, are somewhat dependent on the final factor, acceptance. This refers to the patient's ability to accept that the consequences of their illness are inevitable and that allowing attempts to control them to dominate their lives will simply encourage further biographical disruption (Bury, 1982) or loss of self (Charmaz, 1983).

An increased acceptance of illness has found to be linked to greater understanding of the illness and the reasons for the changes in life situation (Ohman et al., 2003). Clinicians must therefore give suitable information and explanation, as best they can in some circumstances, to allow for acceptance and prevent poor adaptation. Acceptance can also be influenced by felt or enacted stigma. If it is affected by stigma it can have a negative effect on the individual.

The acceptance of the diagnosis and perceived stigma of epilepsy has been shown to result in information control (Scambler and Hopkins, 1986). The individuals with epilepsy often refused to divulge their condition to significant other parties such as employers or work colleagues, ultimately causing negative effects. Similar research with asthmatics (Adams et al., 1997) found

[3] In this study the RDC (Dworkin and Le Resche 1992) criteria were simplified to muscular (myofascial) and articular (Arthritidites and Disc Displacements) groups

two main groups of patients “the accepters” and “the deniers”. The accepters had reconstructed themselves using positive role models and viewed asthma as part of their everyday lives and something that could be controlled. The deniers rejected the notion of asthma on the basis of the negative image they had of asthma sufferers; they felt discreditable. This “discreditability” limited their acceptance of their diagnosis and its prophylactic management. They reconstructed their identities along the lines of “bad chests” and acute illness to avoid membership of a group they felt were stigmatised. Clinicians must, therefore, be aware of any potential stigma cues they may offer when giving a diagnosis, especially one that can be linked to stress, such as TMD.

It has been suggested that lack of acceptance of the illness can, therefore, sometimes lead to poor psychological adaptation to the illness. This can result in increased (reported) pain, increased psychological distress and physical disability (Keefe et al., 2004). The three main psychological processes involved in poor psychological adaptation are pain catastrophisation, helplessness and pain related anxiety and fear.

Pain catastrophizing is when the individual focuses entirely on their inability to manage their symptoms and worries over the negative consequences of that inability, despite the often small likelihood of those consequences occurring (Turk, 1999; Turner et al., 2000). Catastrophisation been suggested as a maladaptive coping strategy (Keefe et al., 1989) and has been associated with increased psychosocial disability and higher levels of depression (Severeijns et al., 2001; Turner et al., 2000, 2001, 2002).

Physical disability was found to be independently predicted by the level of catastrophisation in chronic pain patients (Turner et al., 2000) meaning that their condition can be worsened by maladaptive coping. Turner et al (Turner et al., 2001) had similar findings in TMD patients who catastrophised about their pain. They found significant associations between catastrophisation and activity interference, depression and non-masticatory jaw activity limitations e.g. laughing. Catastrophisation was found to be an exacerbating factor for, and an important predictor of, momentary pain in TMD patients (Litt et al., 2004). This means that not only can catastrophisation in TMD focus the individual on their complaint but it may worsen it too.

The next factor, helplessness, follows on from catastrophisation and can be worsened or initiated by it. Helplessness occurs when an individual assumes a fatalistic approach to their symptoms and illness and they suspend all active attempts to manage them. In this sense it is the inverse of self-efficacy. In the development of an index to measure degrees of helplessness in Rheumatoid arthritis (Nicassio et al., 1985) helplessness was found to be related to depression and disability independent of the severity of the disease.

In examining the concept of helplessness, consideration has to be given to the fact that the patient may only be exhibiting this as they feel a lack of social and professional support, due to discreditation. This lack of support will make them feel helpless in their societal functioning, as they will still have to struggle to maintain everyday functioning against a backdrop of symptoms

they cannot control. Uncertainty over the course, aetiology and nature of Fibromyalgia has shown to increase the level of helplessness exhibited (Nicassio et al., 1999). This would seem to support the role of a lack of social support, due to lack of legitimacy, in initiating or increasing levels of helplessness. These high levels of helplessness in Fibromyalgia mediated health status by increasing the levels of disability.

TMD can be viewed as sharing many of the uncertainties of Fibromyalgia and it could be hypothesised that TMD patients may also have high levels of helplessness. This has been demonstrated when TMD patients' levels of distress and coping were examined (Ferrando et al., 2004). Lack of perceived control over symptoms has also been found to be high in TMD patients (Stockstill and Callahan, 1991; Turner et al., 2001) and this could predispose towards a tendency of helplessness.

The final factor "negatively" affecting psychological adaptation, pain related anxiety and fear, could also be linked to the previous other two factors. It occurs when the individual has so much concern over the onset of pain due to their illness that they engage in pain avoidance behaviours. However, if they already have insurmountable pain, it is only evolutionarily normal to be fearful of further exacerbations of the pain and to try and reduce their occurrence. The behaviours that sufferers engage in due to their fear and anxiety which seek to limit the frequency or severity of further exacerbations can, however, be more disabling than the pain itself (Waddell et al., 1993).

"Maladaptive coper" is a labelling from a clinical perspective and exhibits negativity. These people are looking for an explanation and a meaning for their illness and are attempting to control its symptoms. If they have little to no information on how to behave or adapt, all they can try is a process of trial and error, something mankind has done for centuries; can this then be termed maladaptive in the wider sense? It is more ineffective than maladaptive, as some patients do find behaviours, that although odd to society, work for them. If this is the case and medicine has little to offer, are there any benefits of cajoling or coercing them towards the perceived norm?

Attitudes towards pain have been found to be significantly correlated to physical disability and depression (Turner et al., 2000), with increases in physical disability and pain if attitudes are poor i.e. passive and fatalistic. TMD patients have been shown to allow their beliefs about pain to significantly interfere with their social functioning (Turner et al., 2001). However, there is no quantification of the feedback of social functioning on beliefs and behaviours. This too may play a significant role via modelling and social persuasion in changing behaviour. Again the perspective needs to be widened from assuming these individuals are maladaptive due to their condition and psychology, to a view that society and its implicit or explicit handling of these individuals may affect their condition and psychology.

Adaptation, a dynamic or static state?

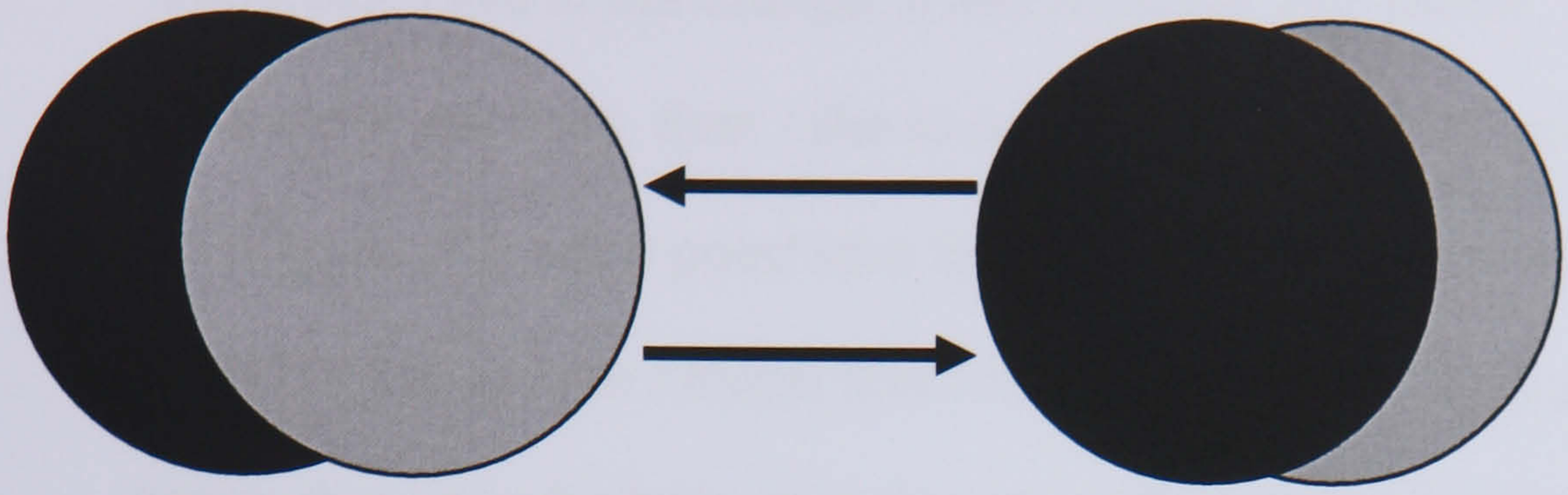
Thus far it would appear that there are two distinct states that an individual with chronic illness can exist in: successful adaptation or poor adaptation.

However just because an individual initially adapts "poorly" to a chronic illness does not necessarily mean that they will not learn to develop coping strategies for it and eventually adapt to it successfully.

This process of moving between these states has been termed the "Shifting Perspectives Model of Chronic Illness" (Paterson, 2001). This model, the result of metasynthesis of qualitative data on chronic illness, adopts two distinct positions for the chronic illness sufferer: wellness in the foreground or illness in the foreground (Figure 2-1). Wellness in the foreground occurs with successful coping strategies and adaptation, whilst illness in foreground, occurs with failure of coping strategies ("maladaptive coping strategies").

Illness in the foreground is characterised by focus on the illness, suffering, loss and burden. Wellness in the foreground is characterised by a focus on managing the illness and rebuilding self, independent of the illness, the outcome being increased reports of a sense of appreciation for life. The movement between these two perspectives is depicted in Figure 2-1.

Figure 2-1 - Shifting perspectives model (taken from Paterson 2001)



Wellness in the foreground

Illness in the foreground

For patients to maintain wellness in the foreground they must firstly have perceived control over the effects of their illness. Secondly they must maintain a focus on day-to-day living irrespective of their illness, rather than perceiving day-to-day living as a result of it. Without maintaining these two factors coping strategies may fail.

There are a number of paradoxes that may occur with this model (Paterson, 2001). For example, to maintain a wellness in the foreground an individual has to maintain a distance from the symptomatology of their illness. This may mean that the illness worsens without them reporting it, which in turn causes a shift in perspective. In addition to this, the need for therapy, or therapies themselves may also cause a shift in perspective, as they often demand an illness in the foreground stance to justify further intervention or to discuss matters at a self-management group. Paterson expresses caution over accepting this model dichotomously in her keynote address (Paterson, 2003), when she referred to the critique of the model by a chronic illness sufferer

who explained the different perspectives as follows:

> *"Generally, I live in the orange. If red is illness and yellow represents wellness, then I like to be a blend of both things. In the orange. It is not a good idea for me to be completely in the yellow because then I forget that I have MS and I do stupid things that I pay for later. And if I am totally in the red, I am too depressed to do anything. I never stay completely in the orange but it's where I like to be and where I try to be. Other people might like to be a little pinker or more yellow" (Paterson, 2003)*

This shifting perspective has been quantitatively demonstrated when quality of life measures have been used with individuals suffering from a chronic illness (Allison et al., 1997). These individuals appear to display a better quality of life than might be expected, this is due to their adaptation to the consequences of their illness. This "response shift" has been noted and there are statistical methods to minimise its impact (Sprangers and Schwartz, 1999). Alongside this it is important to understand that the context, value, and timing of quality of life measures are highly subjective (Ong et al., 2006) probably because of the shifting perspective.

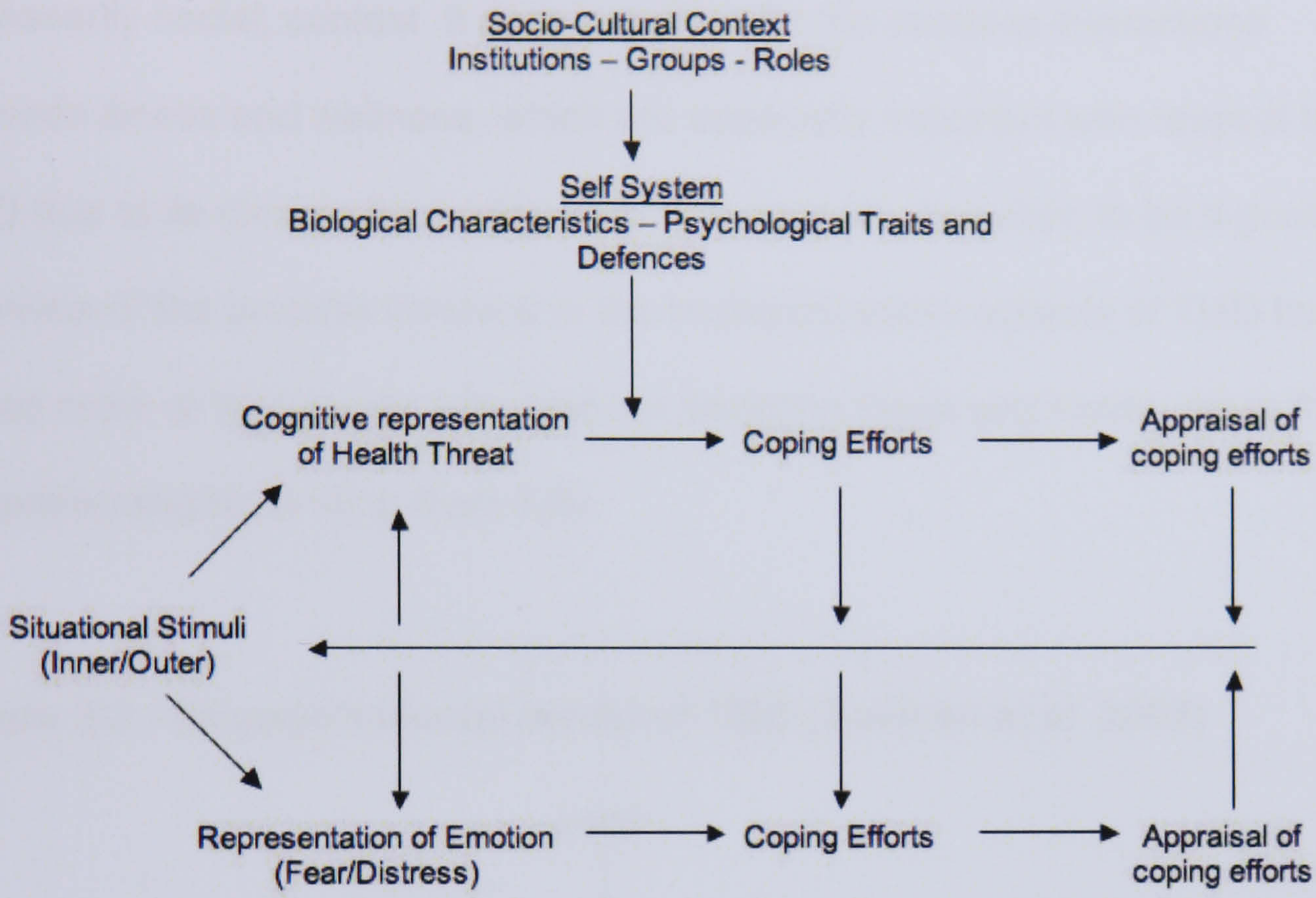
The perspective a patient takes can change and a large factor in this change is the perceived control over the illness and therefore successful coping strategies. Clinicians should be aware, therefore, of the perils of instigating therapies that might change the focus of the individual.

2.3.4 Models of chronic illness progression

Qualitative research illustrating the progression of chronic illness, from genesis to adaptation, supports the assertion of a state of flux between wellness and illness and the involvement of social and psychological factors in this flux (Goodman et al., 2005; Gullacksen and Lidbeck, 2004; Salick and Auerbach, 2006; Shaul, 1995; Theo John Pimm, 1998; Velez and Ramasco, 2006). The data in these qualitative studies can be generically grouped into phases of the chronic illness: Prediagnosis (preconsultation), Diagnosis, Adaptation, Rebuilding and Maintenance. Within each stage the different illnesses cause similar effects on the individual. In the case of the chronic illnesses which are not necessarily physically manifest there are recurring issues with legitimacy and this suggests that the medical profession may have difficulty in helping patients adapt to such conditions.

It is easy to see in these studies the interplay between social occurrences/events and psychological state. This interplay tends to move individuals from focussing on their illness back to adapting to it again (illness to wellness in the foreground). Environmental and social context in relation to chronic illness progression and adaptation has been shown to be important (Williams, 2000). The simplicity of the shifting perspectives model (Paterson, 2001) is very attractive but it does not allow for these environmental contexts to be adequately accounted for. The "Self Regulation Model" proposed by Leventhal et al (Leventhal et al., 1992; Leventhal, 1970) is similar to the shifting perspectives model but allows for environmental and social factors to influence the continuum of adaptation to chronic illness (Figure 2-2).

Figure 2-2 - Self-regulation model (Leventhal et al 1992)

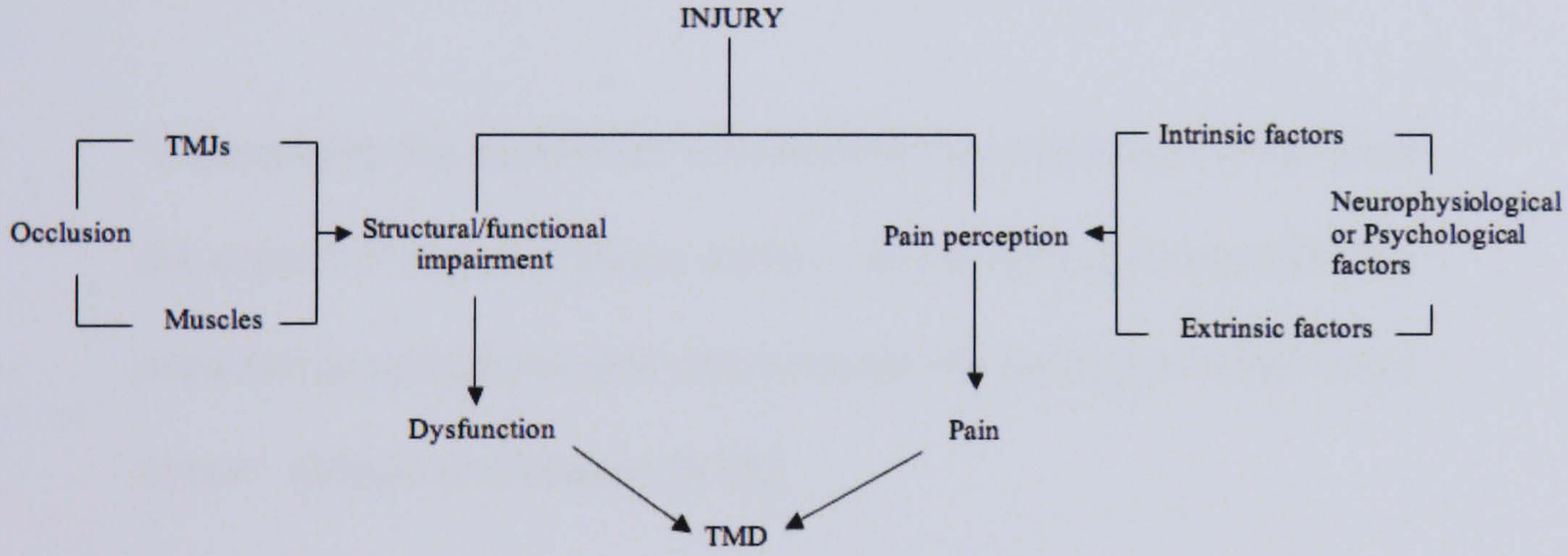


The inclusion of social and psychological factors in any model is important in both TMD and chronic illness generally, because there is a need to understand and identify the point(s) at which these factors influence the progression of or adaptation to the illness. This understanding will allow targeted intervention at these points to prevent worsening of a condition that is already difficult to manage by conventional biomedical treatments.

Leventhal's model seemingly accounts for the interaction between the adaptation processes and environmental and social influences that may occur during the course of a chronic illness. It does not however explain in depth the social consequences of being ill.

Looking specifically at TMD, the biopsychosocial model (Figure 2-3) proposed by Suvinen et al (Suvinen et al., 2005) is the result of a review of the available literature on the biopsychosocial effects of chronic pain and TMD. It allows for linear unidirectional adaptation to the illness and for environmental, but not necessarily social, context. It does not allow for the complex interactions between illness and wellness, which are especially important with respect to TMD due to its chronic fluctuating nature. It appears, however, to be a good overview of the process involved in the biopsychosocial aspects of TMD but is aimed more at therapeutic interventions targeting these processes rather than understanding/illustrating them fully.

Figure 2-3 - Biopsychosocial model of TMD (Suvinen et al 2005)



The academic arguments behind the various models are interesting, but the key messages in the literature for clinicians who manage chronic illness must not be lost in the argument. The first is that clinicians must learn to recognise chronic illness within their patients and be able to identify the stage at which the patient is at in adaptation. The second is that they must encourage

adaptive coping strategies within those patients and empathise with their patients' attempts at coping. They must be wary of making value judgements and labelling patients on the basis of clinical terminology e.g. recalcitrant TMD patient, and they must ensure that social and professional support is continued. The final message they must heed is that adaptation and maintenance are a dynamic process, with a shifting perspective dependent on a number of factors and they must therefore be vigilant for changes within their patients.

2.3.5 Management of chronic Illnesses

Management of chronic illness is very much dependent on successful adaptation of the patient to their illness and therefore must be patient centred:

> *"Conceiving the patient as a experiencing individual rather than the object of some disease entity…involving exploring both the presenting symptoms and the broader life setting in which they occur" (Mead and Bower 2000).*

This need is encapsulated in a quote from McWhinney's paper (McWhinney, 1986) on the emergence of patient centred management:

> *"There is no empirical test for patient's perceptions of their illness, the quality of their relationships or their feelings of responsibility."*

Over the last twenty to thirty years a patient centred approach has been gradually adopted alongside more biopsychosocially minded clinicians (Engel, 1977, 1980). McWhinney's quote recognises this and goes on to state the need for professional and patient interaction/dialogue to ascertain the effects of the illness to allow for management. It is only through this interaction can the clinician gain some estimation of the effects of the illness and what questions the patient wants answering. Only once these are known can the clinician begin to assist the patient towards (self) management of the condition in an egalitarian manner.

The paternalistic "doctor-patient" relationship described by Parson's sick role (Parsons, 1951) has been discussed briefly in previous sections. It is now by no means the norm. However, elements of it will still exist, with clinicians expecting subservience to and acceptance of their knowledge. The move towards patient-centred management requires an egalitarian approach, and the term "patient-professional interactions" is suggested as a replacement for "doctor-patient" (Bury, 2004). This removes the unidirectional insinuation and recognises that it need not be a doctor assisting with a chronic illness. If patient-professional interactions are successful this can have a major positive impact on the patient's experience of their illness.

To any interaction there is a verbal and non-verbal element. The verbal element on the professional's behalf will revolve around obtaining a good history, often with an exceedingly biomedical orientation. This involves

eliciting the patient's complaint, its symptoms, duration and onset at a minimum. This type of consultation has been shown to have flaws (Clark and Gong, 2000) including the fact that patients do not necessarily always volunteer all the effects their illness is having.

Research investigating what constitutes a good consultation in chronic pain (Laerum et al., 2006) found several discrepancies between the patients' perceived and actual expectations of the consultation. The wide-ranging professionals group questioned, emphasised the formulaic aspects of the history taking and clinical examination. The patients questioned perceived that these two aspects had been thorough and satisfactory in their consultation; their demands were, however, different. They wanted an explanation and acknowledgement of their problem and a discussion of the psychosocial effects they were experiencing. The explanation they wanted related to the reason for their pain. They were happy to accept this with or without a diagnosis but they needed further explanation on whether the condition/cause was serious/sinister. This desire stemmed from a wish to enable self-management of their complaint and to enhance their functioning in the face of the illness.

Professionals can, however, inadvertently impose their own interpretations of importance on the verbal communication given by patients suffering from chronic illnesses (Hewlett et al., 2001; Holmes et al., 2001; Rothwell et al., 1997). In these studies the professionals suggested that physical functioning and role limitation were the most important effects of chronic illness to

address. This was in direct contrast to the sufferers questioned, who perceived their vitality, general health, personal impacts and mental health as the most important. Further to this, the misinterpretation of relative importance by the professionals causes a lack of reassurance in patients over their complaint (Donovan and Blake, 2000).

Psychosocial cues in consultations are missed even with prompting from the vast majority of sufferers (Ring et al., 2005). It is possible that this is due to the professionals' conditioning to chronic illness. They may seek to distance themselves from symptoms they can neither explain nor cure fully (Prkachin et al., 2001). In doing this, however, there is a possibility that they fail to explain and legitimise these symptoms resulting in a vicious circle for the patient with worsening symptoms and continued obligation against lessening social support.

In research attempting to frame the "doctor-patient relationship in chronic illness" (May et al., 2004) a large amount of the relationship was found to be based on the modes of "disposal" for the patient, essentially palliation or referral. When disposal was more complex the emphasis of the management then became one of containment of expression of symptoms and the empathy of the practitioners diminished. The practitioners felt that the patients entered a "holding pattern" because the epistemological authority of medical knowledge had been threatened by the lack of explanation of the cause of the illness. The practitioners felt this resulted in little further progress in management.

> *"They [patients with chronic illness] just seem to be stuck with the belief that they have something wrong, and they can't move forward. They can't move forward in their own lives because they've not accepted it, and you are unable as a GP to help them. So both ways you are stuck. It means that perhaps they will continue to consult, but at the end of the consultation you are still no further on." (May et al., 2004)*

If the professional and the patient had different models for the causation of their illness, for example, psychological versus organic and congruence could not be achieved then again the management became one of containment. This all has implications for society's perception of the sufferer, who may then be labelled as a malingerer or one who is awkward for questioning the epistemological authority of medicine.

As patients seek to be empowered, through information, to self-manage their condition (Laerum et al., 2006). It is important, therefore, to involve them in the decision making process towards managing their condition, especially as they are the experts in the effects it exerts (Tuckett et al., 1985). Involving the sufferer in the decision-making may make illegitimacy much less likely as the patient feels justified and involved. Charles et al (Charles et al., 1999a, b) outline shared decision making as one of the three mechanisms by which decisions are made in clinical settings; the other two being informed and

paternalistic decision making. Shared decision making has four necessary characteristics (Charles et al., 1997):

1. At a minimum the clinician and patient are involved in the whole of the decision making process
2. They both share information with one another – so psychosocial effects can be discussed and attended to in any decisions made
3. They both express treatment preferences and try to resolve to a common denominator management
4. A treatment decision is made and both agree to implement it.

There are, however, "grey areas" in decision-making and intermediate approaches, falling between paternalistic and shared decision making, may be necessary in certain circumstances. Wherever possible and especially in chronic illnesses where a "cure" is not always the target, shared decision making should predominate. This ensures the patient is managed according to their needs and expressed difficulties rather than their perceived ones. This "therapeutic alliance" is key to allow the patient to adapt to their chronic illness and is now recognised by most clinicians (Charles et al., 2003).

The clinician's role in chronic illness, in the absence of curative action, is determined by the principles of patient centeredness (Mead and Bower, 2000). This is due to the need to empower patients to help themselves. For this to be successful, management must be centred on the patient's reported problems and they must help make the decisions regarding management, as

far as is possible. The patients will then learn, in this supportive environment, to adapt and self manage their illness.

Self-management and its effects

The concept of self (or collaborative) management came about through work Kate Lorig and her colleagues did at Stanford University, which showed that it decreased the demands on the healthcare system (Lorig et al., 1985). This is attractive for any healthcare system, particularly one with bed shortages such as the NHS. Holman and Lorig (Holman and Lorig, 2000) summarise the effects of a self-management program as: reducing symptoms; improving physical activity; and significantly decreasing the need for medical treatment.

Self-management has been defined as "the ability of the patient to deal with all that a chronic illness entails, including symptoms, treatment, physical and social consequences, and lifestyle changes" (Coleman and Newton, 2005). It is for the most part, a process of education. This education should provide patients with the ability to identify problems, make decisions on those problems and utilise strategies to deal with those problems. The strategies they are taught and use should be applicable to all the challenges patients may face in self-management: medical, social and emotional (Bodenheimer et al., 2002; Coleman and Newton, 2005). Self-management is therefore based around five skills (Lorig and Holman, 2003) that deal with these three challenges:

1. Problem solving
2. Decision making

3. Resource utilization
4. Forming patient/health professional partnerships
5. Taking action

At the centre of self-management is the ability to problem solve within the context of the illness. For example the problems with asthma relate mainly to exercise and medication whereas the problems with depression relate mainly to social activity. Patients having undergone self-management training must be able to define problems clearly, set realistic objectives/action plans, and contact health care support if necessary (Von Korff et al., 1997). Individuals will become either active or passive self-managers (Jerant et al 2005). Passive self-managers seek a paternalistic professional-patient relationship and don't put coping strategies in place. Those who are active self-managers adapt well by using efficacious coping strategies and seeking shared decision making with the professional.

Ongoing support for self-management is important to allow ongoing success. The supporting mechanisms should involve clinician's action and health care system changes (Coleman and Newton, 2005). Clinicians should seek to address health literacy issues to allow patients to access resources more effectively. They should try to ascertain the patient's perspective of the problems they are experiencing and help to set realistic goals. Wherever possible they should make efforts to link patients to community-based self-management resources.

The effects of self-management were first noted in the outcomes of a self-help educational program for individuals with arthritis (Lorig et al., 1985). Individuals who had attended the Arthritis Self-Management Program had significant increases in their knowledge of self-management techniques, their levels of exercise and relaxation. They also reported significantly less pain in comparison to the controls, however this was measured by a visual analogue scale and the paper quite correctly urges caution in the results' interpretation. These effects have been found to be long-lasting over four years with or without reinforcement (Lorig and Holman, 1989; Lorig et al., 1993). The patients reviewed after the four-year period had significantly less: visits to health care professionals; depression; and pain. They also exhibited significantly greater self-efficacy.

Other studies (Lorig et al., 1999b; Trojan, 1989; Winkler et al., 1989) including meta-analyses (Deakin et al., 2005; Gibson et al., 2003) have looked at the effects of self-management programs similar to the ASMP on different chronic illnesses. All have found benefits to health outcomes in the individuals involved in the programs due to the commonalities between different chronic illness effects and experiences. The effects have not differed either with culture or country (Lorig and Holman, 2003) and are independent of whether professional or lay educators are used for the program (Lorig et al., 2001b).

The effects of self-management seem well documented and substantiated by the literature. There have, however, been anecdotal criticisms of the validity and reliability of the trials conducted into the use of self-management. These

are recognised and dealt with by Lorig (Lorig, 2003) in her Editorial for Medical Care. It is natural and correct scientific practice to question any new intervention. Self-management, however, has proven non-invasive, beneficial, inexpensive, long-lasting and exerts positive effects for conditions that are at present incurable and that modern medicine has struggled with. Undoubtedly, however, it like any intervention, is not a panacea for all and there are identified barriers to self-management (Bodenheimer et al., 2002; DoH, 2006; Jerant et al., 2005; Rogers et al., 2005).

Self-management is not a "one size fits all" modality and its use must be tempered by discussion with the patient to establish their preferences. It may be that those who expressed a wish for paternalism are still searching for legitimacy and once this is received they will be willing to enter into self-management. However the inverse may also be true, in that they may perceive self-management, due to lack of public awareness, as a discreditable solution to their complaint. Perhaps before its wholesale implementation, more work is required into the public perception of self-management to ensure it is not discreditable due to its non-biomedical nature.

In the U.K., however, since the 1980s a number of initiatives have been put in place to further the patient's role in the healthcare system (DoH, 1999, 2001, a) and in 2001 a nationwide self-management program was started "The Expert Patients program" (DoH, 2001). It aims to create "Expert Patients" to facilitate self-management in other patients with the same illness and the Government intends it to be the first tier of intervention for individuals with

long-term conditions (DoH 2005). Early results (DoH, 2006; Kennedy et al., 2007) show benefits similar to the self-management programme it is modelled on (Lorig and Holman, 2003). The Expert Patient programme has, however, been the source of consternation for some clinicians (Badcott, 2005; Fox et al., 2005; Shaw and Baker, 2004; Tyreman, 2005; Wilson, 2001). This aside, it may be something that is applicable to, and possible to institute for, the chronic illnesses in dentistry.

2.3.6 Conclusion

It is clear from the literature that managing chronic illnesses is, from a patient and a professional perspective, complex. The review illustrates a dearth of this type of research in dentistry. It does not mean, however, that there are no chronic illnesses in dentistry. Dentistry, as with other medical specialties, is well-endowed with them; Trigeminal Neuralgia, Burning Mouth Syndrome and TMD to name but a few. It does, however, mean that dentists in general may be unaware of the ramifications of chronic illness on an individual nor indeed the way that these may be managed through a symbiotic partnership with the individual. This lack of awareness may therefore mean that biopsychosocial biographies go unheard, poor coping strategies go unchanged and partnerships remain unformed. If this is the case health and therefore quality of life will surely suffer. It is therefore imperative that research exemplifying these problems brings them to the fore in dentistry and highlights the need for consideration of the wider implications of chronic illnesses and the literature surrounding them.

2.4 How do clinicians make decisions?

The success or failure of any clinical intervention depends on whether there are interventions that work and whether or not the professional makes the most appropriate decision on which one to use. In TMD this decision making process is hampered by the poor quality of the scientific evidence (Section 2.1) which can make it difficult to make a diagnosis and difficult to choose the appropriate intervention.

There are two common theories on how clinicians should make decisions, the prescriptive and descriptive (McKinlay et al., 1996). The prescriptive is where clinicians make decisions on carefully calculated probabilities based on evidence and adjusted by Bayesian[4] statistics to the individual patient. The descriptive is more subjective to the clinician, allowing for environmental, social, patient and clinician factors to influence/modify the decision in a positive or negative manner.

2.4.1 Prescriptive decision making

This scientific or rational model of decision-making was initially commonplace in nursing, where nurses utilised decision trees or algorithms to make clinical decisions (Luker et al., 1998). These decision trees were the result of probability calculations of each individual outcome of different decisions.

These decision trees have now become more widespread throughout the

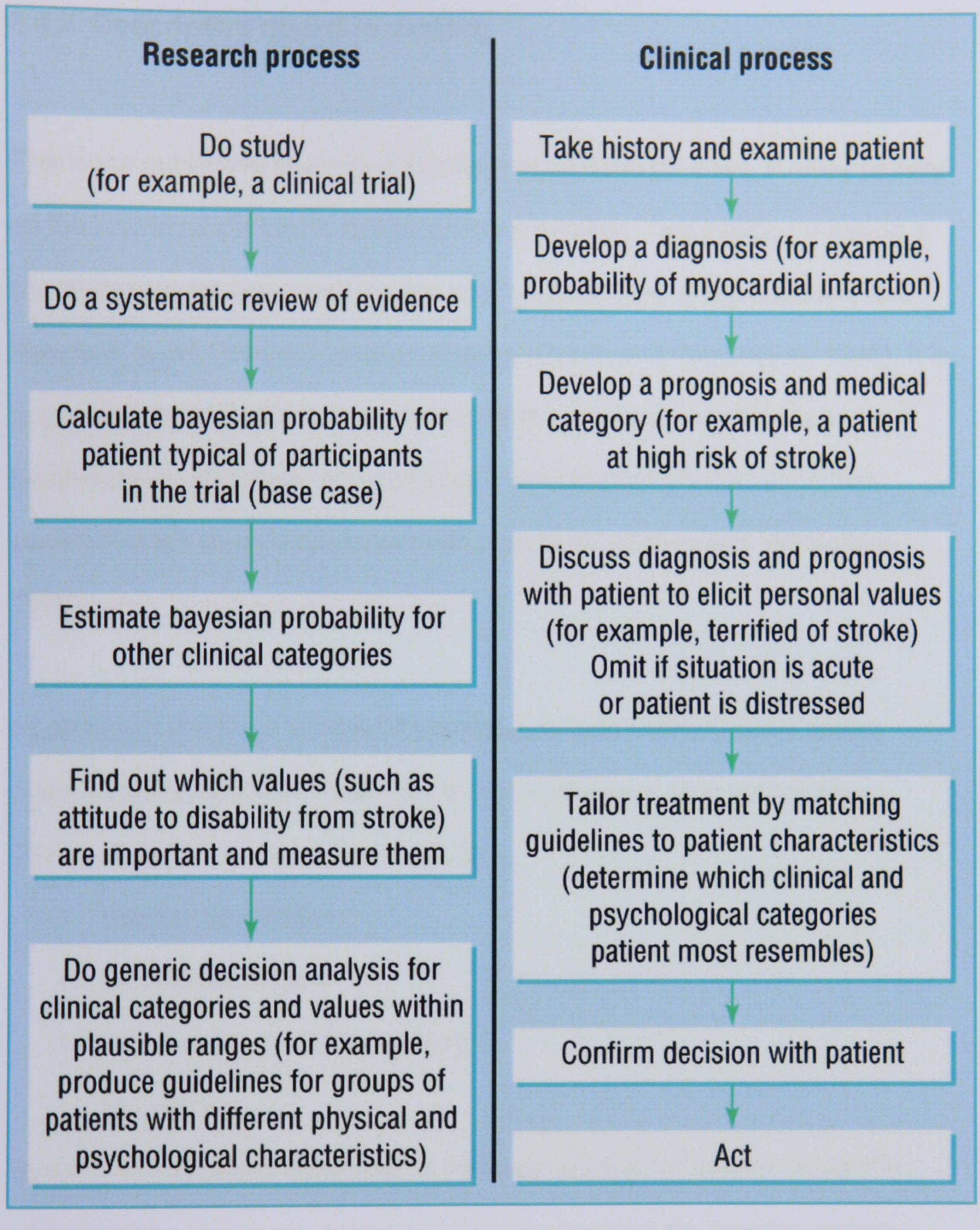
[4] This is a branch of statistics that utilises the knowledge of prior events (data from research) to predict future events.

medical profession resulting in a number of clinical practice guidelines in dentistry and medicine (Muller et al., 2003; van der Sanden et al., 2004).

Decision analysis utilises probability estimates from data generated by studies and patient values (utilities), to help decide the best outcome. Patient values are an indication of a patient's preference for one outcome over another. It is beyond the scope of this review to examine in detail the mathematics behind decision analysis but it is possible to illustrate the process behind it (Figure 2-4).

In reality the recent evidence (van der Sanden et al., 2005), suggests it takes more than simply having a guideline to get clinicians to use it.

Figure 2-4 - Process of decision analysis, taken from (Lilford et al., 1998)



2.4.2 Descriptive decision making

This is the subjective alternative to prescriptive decision trees. It relies heavily on the individual clinician's experience and intuition. This intuition relies on a sound knowledge base, experience and a holistic view of the situation, and therefore, is not irrational decision making (Easen and Wilcockson, 1996). It is suggested that this intuition bypasses the linear reasoning process and is a "spontaneous, effortless, non-conscious, unexplained phenomenon that occurs through deep involvement with a problem" (Easen and Wilcockson, 1996).

Intuition can involve a number of strategies to help problem solve and/or make a clinical decision, these can be used singularly or in conjunction.

These strategies are (Croskerry, 2002):

- Pattern recognition
- Exhaustive method
- Hypothetico-deductive method
- Heuristics.

Specific history and/or examination features can lead to pattern recognition and a working diagnosis, which can then be used to help decision-making. Top-down data, such as clinical investigations can be used to supplement the pattern recognition processes. An example of such a process would be a patient who presents with drooling and an anterior open bite and has previous

difficulty with recurrent dislocations of their TMJ. The clinician might recognise a dislocation from the pattern but might seek further top-down data from a radiograph to confirm the dislocation.

The exhaustive method is common amongst novice clinicians and involves gathering all possible data regarding the presenting condition to the point of exhaustion. The novice often adopts this approach due to their level of uncertainty in the possible diagnosis or decision. They will gather all manner of data, which may or may not be pertinent to or directed at the presenting complaint. The method is not exclusive to the novice as the experienced clinician may adopt it when there are high levels of uncertainty, either to gain thinking time, or to rule out all possibilities (Croskerry, 2002).

The hypothetico-deductive method utilises induction and deduction. The induction from the presenting data from history and examination results in a hypothesis. The generated hypotheses are then used deductively to ascertain any missing data, which could confirm one of the hypothesis (Buckingham and Adams, 2000). If the patient presenting with temporal pain is taken as an example, the clinician may have in their mind a list of differential diagnoses. They would then seek to confirm or disprove these diagnoses (hypotheses), by pertinent questions in the history and examination/investigation of the area.

Heuristics are a product of experiential learning, that is, they are "rules of thumb" developed through clinical practice. They are decision-making

shortcuts, which in the main work well due to experience, but do have some shortcomings. These will be discussed later.

2.4.3 Influences on decision making process

Clinical decisions have nearly always been prone to external or internal influences during the process of making them. The main influence on prescriptive decision-making is the standard of available evidence to formulate clinical practice guidelines to prescribe decision making. If TMD is taken as an example, the majority of systematic reviews of treatment modalities have come to the same conclusion, that it is not possible to draw conclusions and more data are required (Al-Ani et al., 2004; List et al., 2003; Olivo et al., 2006; Shi et al., 2003). It may, therefore, be impossible to construct a clinical practice guideline where the evidence is poor or scanty.

The other shortcoming of using prescriptive decision-making is that it only allows biomedical and objective findings, symptoms of presentation and probabilities of disease, to be included in the decision-making process (McKinlay et al., 1996). In doing so there is the potential to grossly over-simplify the condition and miss its social or environmental context, which has proved important in TMD (Di Fabio, 1998; John et al., 2002a).

Descriptive decision-making, in contrast, is a subjective process and can take account of the social and environmental context, but therefore is also affected by a large number of influences, which can be grouped into three distinct groups (McKinlay et al., 1996):

- Patient characteristics
- Clinician characteristics
- Practice characteristics

Patient characteristics

As any clinician is aware all patients have widely varying characteristics and it is unsurprising, therefore, to find that patients' characteristics affect clinicians' decision making. Two of the more repeated influences through the literature are race and socioeconomic status. In a study controlled for socioeconomic class (Cabral et al., 2005), it was found that dentists were more likely to prescribe extraction than restoration for a decayed but restorable molar tooth in a black patient. This prescription remained unaltered irrespective of the dentists' sociodemographic characteristics. The study concluded that there may have been a degree of socioeconomic stereotyping of black patients and that this is of concern as socioeconomic information is often incomplete on patients in the practice setting. In a study into the patient-physician relationship (Cooper-Patrick et al., 1999), the Afro-Caribbean patient was found to have less participatory visits with their physician potentially compounding the stereotyping described by Cabral et al.

Socioeconomic status also appears to predispose clinicians' decisions towards more radical treatment planning, with significantly higher extraction and prosthodontic rates in lower socio-economic classes (Brennan and Spencer, 2005). This may be due to disparities in oral health between the socioeconomic classes or it may be due to stereotyping the patient as

possessing a low value on their dentition or it may be a product of both. As the patient's age increased, dentists were found to have increasing tendency towards extraction, although this could be explained by poor prognosis after multiple restorations rather than the value the dentists placed on retaining teeth in the elderly.

The data in the study by Brennan and Spencer (Brennan and Spencer, 2005) is from outside the U.K. but would seem to be supported and explained by some of the findings of the 1998 Adult Dental Health Survey (Treasure et al., 2001). In terms of socioeconomic status (class IV and V), this survey found there were higher rates of edentulousness and partial dentitions in the lower socioeconomic groups. Socioeconomic gradients were observed, but to what extent these are the result of patient behaviours as opposed to professional decision-making is unknown.

The primary concern of a clinician is generally for the patient and clinicians strive to achieve resolution of patients' problems. In doing so they make decisions relating to the treatment of the patient. These decisions are often made on the basis of the formulaic history the clinician has taken from the patient which tries to identify both the source and the scale of the problem and its impact on daily life. Recently, however, this information has been shown to be an insufficient base for decisions relating to treatment (Holmes et al., 2001). This work involving patients suffering from migraine has shown that a physicians' perception of patient disability gleaned from the history[5] is

[5] Process of eliciting from the patient in a consultation their problem and its effects

inaccurate. This is possibly due to the lack of questions about the disabling effects of the condition in the history and the lack of patient communication of the level of disability. Reassuringly, once the information was gathered by a patient based quality-of-life measure (M.I.D.A.S) and presented to the physicians they altered their decisions regarding treatment. This perhaps suggests that QOL measures have a role to play in informing clinicians' decision making, especially in relation to choosing which intervention to employ as they will highlight the areas patients are affected by the most.

Clinician characteristics

The main characteristics of a clinician that can influence the decision-making process are summarised in Table 2-1. Most of the characteristics summarised are linked in some way; experience and uncertainty, heuristics and bias, evidence and clinical practice guidelines. They all appear to be linked to one another by uncertainty.

Table 2-1 - Summary of clinician characteristics that can influence decision making

Characteristics of clinician	Author
Experience	Luker et al., 1998
Uncertainty	Hall, 2002
Use of Heuristics	Croskerry 2005
Knowledge of Evidence/Literature	van der Sanden et al., 2002
Existence of clinical practice guideline	Knutsson et al., 2001; van der Sanden et al., 2004
Bias/ Cognitive disposition to respond	Bornstein and Emler, 2001

If a clinician's experience aids decision-making then their inexperience will certainly detract from it. This is likely to be due to the uncertainty inexperience brings. Intuition is recognised as a large part of decision-making and it is accepted that intuition develops alongside experience (Easen and Wilcockson, 1996; Luker et al., 1998) as the strategies used in intuition (Croskerry 2002), especially the pattern recognition process, would be less effective without experience.

The clinician will invariably try and manage the uncertainty of clinical decision making by a number of approaches (Hall, 2002) including upholding "medical orthodoxy" and therefore conforming to the peer group practice, a safety in

numbers approach. There is also a propensity towards denial of the uncertainty, perhaps in the hope of maintaining the patient's faith.

To manage uncertainty, the clinician may employ heuristics, which are essentially "rules of thumb", mental short cuts (Croskerry, 2005) or "subjective probability judgements" (Tversky and Kahneman, 1974). They are prominent in descriptive decision making especially where there is a degree of uncertainty, urgency or dynamism required (Cioffi, 1997). The three main heuristics used are "representativeness", "availability" and "anchoring" (Croskerry, 2002). The "representativeness heuristic" is the cornerstone to pattern recognition; the presenting complaint is compared to the mental list of signs and symptoms of a condition and a decision is made over diagnosis. In TMD this would be the click on opening and closing for disc displacement with reduction. This diagnostic decision may be made quicker by the "availability heuristic". If a condition comes more readily to mind it is considered more frequent and therefore more likely in the diagnosis. Previous to this point the "anchoring heuristic" could have already confirmed the diagnosis by setting a large amount of faith that the signs and symptoms could represent nothing else other than disc displacement with reduction.

Often uncertainty is not wholly based on inexperience but on a real or perceived lack of evidence on which to base practice (Hall, 2002). Many practitioners are simply unaware of new evidence but have been shown in controlled conditions to change their behaviour when it has been presented to them (van der Sanden et al., 2002). The best mechanism for dissemination of

new evidence is uncertain, (Section 2.4.4), but one mechanism that has had some success are clinical practice guidelines. These have been found to alter practice and aid decision-making (Knutsson et al., 2001; van der Sanden et al., 2005) but cannot be judged to be the universal panacea (Cabana et al., 1999). This evidence-based practice helps reduce the uncertainty in clinical decision-making and does not have to be used prescriptively but can be used as background knowledge in the intuitive process. If there is, however, no current evidence then there will be continuing uncertainty leading to the use of heuristics and the possible incorporation of bias.

Bias comes in multiple forms. These have been best summarised by two papers (Bornstein and Emler, 2001; Croskerry, 2002) and Table 2-2 is a conglomerate of both papers:

Table 2-2 Types of bias

Aggregate bias	Gambler's fallacy	Premature closure
Anchoring bias	Gender bias	Psych-out error
Anticipated regret	Hindsight bias	Regret/outcome
Ascertainment bias	Ignoring negative evidence	Representativeness restraint
Availability	Number of alternatives bias	Search satisfying
Base-rate neglect	Omission bias	Sutton's slip
Commission bias	Order effects	Triage-cueing
Confirmation bias	Outcome bias	Unpacking principle
Diagnosis momentum	Overconfidence bias	Vertical line failure
Ego bias	Playing the odds	Visceral bias
Framing	Posterior probability error	Ying-Yang out
Fundamental attribution error		Zebra retreat

It is beyond the scope of this review to cover every bias in depth but Table 2-3 adapted from Bornstein and Emler's, provides a helpful summary dividing the more common biases in decision making into diagnostic and treatment biases. Croskerry's bias paper (Croskerry, 2002), has a much more in-depth analysis of every bias mentioned in the literature and is a useful reference for further information.

Table 2-3 Definitions and examples of selected biases. Adapted from Bornstein and Emler 2002 and Croskerry 2002

Bias. Other names in parenthesis	Description	Example	Possible Consequence
Diagnostic biases			
Base rate neglect (Representativeness exclusivity)	Clinician makes decision based on how well the patients' presentation fits their mental checklist for a particular condition rather than looking at the likelihood of that condition in that patient.	Clinician diagnoses cluster headache in a female patient due to temporal pain rather than myofascial TMD	This can lead to overestimation of improbable diagnoses
Confirmation bias (Belief bias, Following hunches, Pseudodiagnostically, Positive testing, Effort after meaning, Relevance bias)	Clinician is selective in their evidence gathering and seeks evidence to support (confirm), their hunch/theory whilst ignoring evidence to the contrary	Clinician requests MRI to confirm internal derangement of TMJ in a patient despite the evidence being towards this or myofascial pain	This leads to the pursuit of one diagnosis to the detriment of others thereby wasting resource and resulting in possible misdiagnosis
Availability bias (Regency effect, Common things are common, The sound of hoofbeats means horses, Out of sight out of mind [non-availability)	Clinician mentally increases the likelihood of a condition by the mere fact they have seen a case recently i.e. it readily springs to mind	Clinician assumes acutely presenting patient with an anterior open bite is a dislocation as they have seen a number of cases recently instead of considering progressive Rheumatoid arthritis as a diagnosis	Availability and its counterpart non-availability disproportionately alter mental probability estimates thereby making under or over diagnoses a possibility.
Hindsight bias (Knew it all along effect, Retroscope analysis, Wisdom after the fact, Creeping determinism, Outcome knowledge)	Clinician knows the outcome of a diagnosis and exaggerates the likelihood of making that diagnosis in retrospect	Clinician finds that the diagnosis of temporal pain in a "TMD" patient is temporal arteritis and convinces themselves that this diagnosis would have been made in the original consultation	The clinician develops overconfidence in their decision making/diagnostic ability
Regret bias	Clinician overestimates a possible diagnosis with a severe outcome because of the anticipate chagrin or regret that would occur if the diagnosis was missed	Clinician ordering a head and neck CT to rule out neoplasia in a patient with clinically obvious myofascial TMD	Objectivity reduced and wasted resources

Bias. Other names in parenthesis	Description	Example	Possible Consequence
Treatment biases			
Regret/outcome bias	Clinician feels worse about severe outcomes due to treatment than conservative approach and tries to "watch and wait" more frequently. They also seek to take more credit for positive outcomes from treatment decisions than those leading to severe/adverse outcomes	Clinician feels terrible about one middle meningeal artery bleed due to an eminectomy performed for TMD disc displacement without reduction. They therefore stop doing the procedure and become more conservative despite previous success with the procedure	Alteration in effective practice on non-objective evidence
Framing	Clinician chooses a treatment dependent on the way the relevant statistics are presented to them. If presented in the "domain of losses" they are likely to take more risks	The psychiatrist of a recalcitrant TMD patient tells the clinician managing the patient that there is a high risk of suicide of the patient involved unless something is attempted so the clinician chooses to perform a surgical procedure on the TMJ with high morbidity and low rates of efficacy	Inappropriate treatments chosen and pursued due to alteration in the presentation of the problem
Number of alternatives (Multiple alternatives bias, Status quo bias, Wallpaper phenomenon)	Clinician chooses a treatment option more often because of it pre-existing most of the alternatives	Clinician chooses Dothiepin to manage TMD due to previous practice despite better less sedating alternatives being available now	Anecdotal practice with less efficacious treatments

Practice characteristics

It would seem logical that the environment in which care is provided can affect decision-making. With the increased age of a practice there appears to be a downward trend in the total number of interventions made (Grembowski et al., 1990). This maybe due to the clientele base having been established for a long time and being made dentally fit. The number of procedures per dentist occurring appears to increase with a larger practice along with increased busyness (Brennan and Spencer, 2005; Grembowski et al., 1990) and it would seem this is due to increased throughput of patients. In solo practices the interventions that occurred less frequently were extractions and diagnostic services (Brennan and Spencer, 2005).

Finance is always a key issue especially in dental practice, which is a business. Treatments must be seen as cost-effective against the fee scale, (in the U.K. the N.H.S. fee scale but this would apply in some other systems also) and the time they take. When relative analgesia (titrated nitrous oxide and oxygen) provision was examined in primary care it was found that the practitioners were not averse to the principal of using it but felt that the monetary cost and the cost of the time-spent training were prohibitive (Freeman and Carson, 2003).

Summary of influences on decision making

The recurring theme throughout any critique of descriptive decision-making is the possible subjectivity of the process to the individual and the bias that may result from this. This is not necessarily so if the individual were making a decision based upon high quality evidence. The ability within descriptive decision-making to tailor decisions to individual patients by combining the evidence and the experience of the clinician metacognitively is invaluable. However, prescribing the decision, irrespective of the patient, seems a little dogmatic for experienced clinicians who utilise evidence-based practice. Clinical practice guidelines do have a useful role in reducing uncertainty for the novice/non-specialist and also for the specialist as long as they are not utterly prescriptive. There is a case for concluding that the decision making process cannot really be dichotomised into two separate processes; prescriptive or descriptive. In many cases it is probably an amalgam utilising best evidence to help provide the more robust decisions. In the absence of good evidence (or where the only evidence available is "bad") the decision-making process is much more uncertain.

2.4.4 Improving decision making

Taking the decision-making process as a whole, there are two main generic difficulties:

- Bias influencing decisions
- Uncertainty influencing decisions

Uncertainty would be expected to lead to more bias but bias also exists independent of uncertainty. Any interventions to improve decision-making must be aimed at both difficulties. In theory prescriptive clinical practice guidelines remove the bias and the uncertainty. This may be true in some circumstances, but within disciplines such as dentistry and surgery there is not necessarily a simple dichotomy of choice. This aside, it is still possible for creator or user to bias a clinical practice guideline and there is generally not as yet enough evidence, especially in Dentistry and certainly within TMD (Al-Ani et al., 2004; Koh and Robinson, 2003; List et al., 2003), to create practice guidelines which are fully evidence based and robust.

When this evidence exists (if it ever does) it will have to be used carefully so as not to over-mechanise or over-rationalise the diagnostic and treatment planning process. Such an approach would risk losing idiosyncratic evidence-based practice for some patients (McKinlay et al., 1996). Specifically, sometimes clinician's experience and acumen developed over the years is useful to predict future problems or deal with certain situations outside of a clinical practice guideline which may be incomplete or faulty; for example a second molar tooth with a posterior carious cavity is likely to be difficult to restore unless the impacted wisdom tooth posterior to it is removed, yet the NICE guidelines for removal of wisdom teeth do not include this as an indication for its removal. Surgeons still, however, remove wisdom teeth on this basis when referred (McArdle and Renton, 2006) because of their experience previously of trying to restore that type of cavity.

In research that examined physicians' failure to follow clinical practice guidelines (Cabana et al., 1999) the common reasons behind the failure included the inertia of their previous practice, their lack of agreement with the clinical practice guideline, the clinician's lack of outcome expectancy alongside lack of familiarity or lack of awareness of the clinical practice guideline itself. For the uptake of any clinical practice guideline to be widespread these issues will have to be addressed.

Croskerry (Croskerry, 2005) suggests that "no one size...fits all" in decision-making. Improvements to the decision-making process will, therefore, be examined generically over the next few sections looking specifically at bias and uncertainty. No distinction will be made between descriptive and prescriptive decision-making.

Reducing bias

One of the most obvious methods to reduce bias in clinicians' decisions is to help them recognise their existence. This has been shown reduce the degree of bias (Bornstein and Emler, 2001). It is suggested that this education should start during undergraduate training (Hall, 2002) and carry on into professional practice. Specifically, dentists have been shown to lack insight into the thought processes behind their decisions and the possible role of biases in those decisions (Knutsson et al., 2000). Educational interventions have been shown to reduce dentists' variability in decision-making (Choi et al., 1998). Choi et al examined treatment decisions from a set of standardised bitewing radiographs. After the practitioners had made their initial decisions they were

given a seminar on variations in perception and judgement. A repeat viewing of the same radiographs with slight alterations ensued and there was a statistically significant decrease in variability between the practitioners' decisions.

This seems to support the assertion made earlier, that commoner forms of bias should be illustrated to students and practitioners (Hall, 2002). Avoidance strategies for bias could then be detailed (Croskerry, 2002) allowing the individual to manage bias better. Table 2-4 gives a summary of the avoidance strategies for the more common biases.

Table 2-4 Avoidance strategies for common biases

Bias. Other names in parenthesis	Avoidance strategies (Croskerry 2002)
Diagnostic biases	
Base rate neglect (Representativeness exclusivity)	Clinician needs to be aware of disease prevalence in general and local populations so to make accurate estimates on probability of the representativeness of a presentation being correct.
Confirmation bias (Belief bias, Following hunches, Pseudodiagnostically, Positive testing, Effort after meaning, Relevance bias)	Clinician needs to be wary of excluding non-confirmatory data for the sake of representativeness
Availability bias (Regency effect, Common things are common, The sound of hoofbeats means horses, Out of sight out of mind [non-availability)	Objective data needs to be gathered irrespective of how many cases of X have been seen recently. If the objective data is non-confirmatory the decision/diagnosis should be reconsidered.
Hindsight Bias (Knew it all along effect, Retroscope analysis, Wisdom after the fact, Creeping determinism, Outcome knowledge)	Clinician should not use the "retrospectoscope" to gain over-confidence in decision-making abilities and should take into account the environment in which "bad" decisions were made, to avoid purgatory over them.
Regret bias	Clinician should be aware of the possible over estimating the probability of a severe diagnosis and seek to avoid this unless objective data exists to support the decision to investigate further
Treatment biases	
Regret/outcome bias	Clinician should seek objective data to base decision on and be aware of possible bias from previous adverse outcomes
Framing	Clinician should seek both the positive and negative outcomes of the decision and carefully evaluate them before making decision based on the negative
Number of alternatives (Multiple alternatives bias, Status quo bias, Wallpaper phenomenon)	Clinician should compare each alternatives advantages and disadvantages to the current favoured one and decide which is the most favourable.

Reducing uncertainty, evidence-based practice

One of the key messages throughout the review of the decision-making literature was the role of evidence. Evidence-based practice helps reduce uncertainty (Hall, 2002). This evidence can either be formally applied within clinical practice guidelines or form part of the intuitive process. The evidence,

however, has to be good and the guideline has to be properly formulated for this approach to work.

Evidence-based practice can be defined as the "conscientious, explicit and judicious use of current best evidence in conjunction with clinical experience to make decisions regarding patient care" (Sackett et al., 1996). It has arisen through advances in clinical research including the advent of the randomised controlled trial and the introduction of computerised databases, which allow systematic searching of journals (Dodson, 1997; Goldstein, 2002). Essentially it is an amalgamation of prescriptive and descriptive decision-making. Its aim is to provide the clinician with guidelines based on the best current evidence simultaneously allowing clinical expertise to play a role in the decision-making process. It is not explicitly aimed at allowing third parties to control practice (Goldstein, 2002). It is summarised by the statement "integration of good judgement with best available evidence" (Niederman and Badovinac, 1999)

How do we apply evidence-based practice?

Evidence-based practice is a move away from decisions about treatments that are based on poor quality evidence or convincing and vocal champions (Goldstein, 2002). Its application, therefore, is simple (Anderson, 2002; Niederman and Badovinac, 1999). The first step is to convert a clinical information need into a question such as, "what is the most effective initial conservative management for TMD?" That question can then be broken into its components and the electronic databases searched for journal articles.

Secondary sources can then also be searched, such as the Cochrane Library, for any pertinent systematic reviews. The computerised nature of the search helps reduce any bias and then it is up to the researcher to critique the findings of the papers retrieved to ensure that, methodologically, they are sound. This is generally done in a fairly standardised way according to pre-set criteria. The evidence can then be appraised against the patient's needs and clinical judgement utilised on how to apply the evidence to the decision for the patient. The final step is to audit one's practice to ensure performance is as good as it can be. Unfortunately many systematic reviews simply conclude that there is insufficient evidence to make a valid conclusion and call for quality clinical trials in targeted areas.

Barriers to implementation of evidence-based practice

Each of the barriers will be discussed in turn and they are summarised in Table 2-5. Evidence-based practice is a relatively new concept in Dentistry; it was developed in the late 1960s by Sackett et al at McMaster University but has not, until recently, been prevalent in dentistry (Niederman and Badovinac, 1999).

Table 2-5 Summary of barriers to implementing evidence-based practice

Barrier to evidence-based practice	Author(s)
Recent introduction	Niederman and Badovinac, 1999
Lack of robust evidence in dentistry	Bader et al., 1999
Mixed skills of practitioners	McGlone et al., 2001
Uncertainty over dissemination	Freemantle et al., 2000; Giuffrida et al., 2000; Grol and Grimshaw, 2003; Jamtvedt et al., 2003; Oxman et al., 1995; Shaw et al., 2005; Thomson O'Brien et al., 2000, 2001
External factors influencing clinician – time, finance, patient, social	Cabana et al., 1999; Grol and Grimshaw, 2003; McGlone et al., 2001

The relatively recent introduction of evidence-based practice into dentistry has two major consequences. Firstly there is a lack of robust evidence, such as randomised controlled trials, for the more common treatments in dentistry (Bader et al., 1999). Secondly it means that many practising clinicians are not as familiar with the searching and critique skills as current undergraduates are. Combined with the long half-life of change for a clinician (Niederman and Badovinac, 1999) and the very heterogeneous and complex nature of dental disease, this lack of conceptual understanding stops evidence-based practice being widely implemented in dental clinical practice.

There is still uncertainty over the best mechanism for disseminating established evidence-based practice to the practising profession. Various mechanisms have been tried: Educational materials, conferences, small group teaching, patient mediated interventions and audit to name but a few,

but most have been found to have moderate effects, at best, on changing practice (Freemantle et al., 2000; Giuffrida et al., 2000; Grol and Grimshaw, 2003; Jamtvedt et al., 2003; Oxman et al., 1995; Shaw et al., 2005; Thomson O'Brien et al., 2000, 2001). This may, of course, be related to the mixed skills target audience.

Interventions to increase evidence-based practice within undergraduate education have been more successful; using clinical practice guidelines with dental students caused a significant change in decisions made in relation to asymptomatic wisdom teeth (van der Sanden et al., 2004). However, when a similar study was done using qualified dentists by the same group (van der Sanden et al., 2005) no clinically significant change could be found, although the dentists' knowledge was found to increase. This raises the question whether or not new "Evidence based practice-trained" graduates will continue evidence-based practice and monitor for new evidence to base practice on, or whether they will become less receptive or motivated as their practicing experience increases? Is it possible that the clinicians' gradual progress through the stages of competency from graduate competent to practising expert (Chambers and Glassman, 1997; Hendricson and Kleffner, 1998) enhances the findings of Van der Sanden et al (van der Sanden et al., 2005)? Does the practitioner's previous anecdotally successful practice lead to rejection of evidence-based practice or does their self-perceived expert status lead the dentist to question the efficacy of new evidence-based practice?

These hypothesis are as yet untested in the literature but if found valid then

they could have serious repercussions on evidence-based practice and its teaching.

There may also be external factors affecting the clinician's implementation of evidence-based practice: financial; patient-based; advocacy; social or organisational factors (Cabana et al., 1999; Grol and Grimshaw, 2003; McGlone et al., 2001). Financial constraints have affected the implementation of conscious sedation for children (Freeman and Carson, 2003) and this can be a highly significant factor, as if the reimbursement is not appropriate for the evidence-based practice then it would be very difficult in a business environment to justify any expenditure on it. Patients can also have a bearing on evidence-based practice as they may have been exposed to other treatments previously and not wish to change their usual treatment for the sake of evidence-based practice (Cabana et al., 1999). This again can be a very powerful motivator for the practitioner as the patient is the consumer. The patient may also accept the treatment but then exhibit poor compliance, as the acceptance was somewhat begrudging.

Advocacy for one particular treatment could come from the patient or from suppliers of a product. The most frequent and well-known example of advocacy is the pharmaceutical industry utilising inducements, free samples and advertising to influence the practitioner. Despite the notoriety of the industry with respect to this practice, practitioners' decisions can still be heavily influenced by this (Adair and Holmgren, 2005). Advocacy from the patient can come from social contexts such as the media; for example there

has been a proliferation of television shows showing cosmetic dentistry recently and anecdotally at least an increase in demand for treatments such as whitening. This may have lead to the general publics' increased perception of discoloration of their own teeth (Alkhatib et al., 2004) which may in turn lead to an increase in demand for tooth whitening. Organisational constraints such as the lack of clinical time also place pressure on the practitioner. Within the NHS this has led to complex treatment being perceived as less financially rewarding (Linden, 1998; Morris and Burke, 2001) and that there is less time available for even simple treatments (Chapple, 2004).

Facilitating evidence-based practice

To facilitate evidence-based practice there has to be a realistic interpretation of the barriers to determine which of them can be addressed. One issue that immediately needs addressing in dentistry is the lack of evidence. This means that the cultural divide between researchers and practitioners has to be acknowledged (Haines and Jones, 1994) and researchers must ensure those at the "coal face" are asked regarding their needs for information and relevant high quality randomised controlled trials are conducted in these areas.

It is clear that no one intervention will not overcome all the barriers to the implementation of evidence-based practice but it would seem logical that a "participative, multi-faceted and interactive approach" (McGlone et al., 2001), would probably be more successful than individual measures.

2.4.5 Conclusion

Clinical decision-making is a complex developing subject. It is open to a number of different influences, which can enhance or detract from the process. Neither of the two basic types of decision-making (prescriptive or descriptive) are perfect, and a more combined approach may be helpful. The potential for improvement of decision-making through evidence-based practice is hampered within dentistry by the lack of quality evidence and by a number of other barriers. Another important barrier is the doubt over the best mechanism for dissemination of evidence-based practice. If an effective dissemination mechanism is found it should help reduce but not totally eradicate, uncertainty in clinical decision-making that appears to be one of the major causes of flawed decision-making. In areas such as TMD this should help standardise initial therapy and reduce the uncertainty of practitioners in managing the disorder.

3 Aims and objectives

Aim

To understand the psychosocial consequences of Temporomandibular Disorders and the ideologies behind their management.

Objectives

1. To ascertain the ideologies behind, and rationale involved in, the management of TMD by dental professionals and to link this to the relevant patient experiences
2. To investigate the psychosocial consequences of TMD for the sufferer
3. To develop a conceptual map of patients' experiences of, and their journey through, care.

Programme of work

This involved three qualitative studies (A, B and C) as described in Section 1.

4 Methods

4.1 Philosophical discussion of methods employed in thesis

4.1.1 Introduction

Qualitative research is essentially interpretative in nature and seeks to understand or explain a social phenomenon. A pertinent example is the attempt to explain the rationale behind the management of TMD. It does not try to quantify the phenomenon but seeks to find out the origins of a decision and factors modifying it for example, "Given the evidence base why do so many practitioners use a soft splint for TMD and how were they introduced to it?". The data discovered is then classified and emergent themes detailed to help build a theory from the data. Due to its interpretive nature there are a number of methods of data collection, each suited to different circumstance or phenomenon studied (Pope and Mays, 2006). Samples for qualitative research are normally non-probabilistic and therefore purposive. Purposive sampling seeks to identify a sample with particular characteristics.

4.1.2 Techniques available

There are three broad groups of qualitative methods available, observational techniques, interviews and focus groups (Britten, 1995; Kitzinger, 1995; Mays and Pope, 1995a). I have utilised in depth semi-structured interviews as the primary data retrieval mechanism for the qualitative data in this thesis. This method gives an individualistic account and allows investigation of the ideologies, experience and rationale of the interviewee in detail (Burgess and

Bryman, 1994). Clearly interviews lose the anonymity of a group and might be perceived as more threatening by the respondent, however this can be minimised by use of a "safe" setting and careful interview technique. The accepted gold standard for these interviews is to audio-record them thereby allowing transcription verbatim and I adopted this in my work.

The difficulties of using either observational techniques or focus groups instead of interviews include: practicality of time constraints for observation; logistics of following a patient through their referral pathway and experiences of TMD; logistics of convening and selecting groups of practitioners or patients; groups causing further somatization in patients, or becoming therapy; groups being biased by charismatic individuals; lack of in-depth focussed intrapersonal data collection with groups.

Qualitative method combinations are possible and can be very productive, the most productive for use in this thesis would be interviews followed by appropriate focus groups. This would allow discussion of recurrent issues from the analysis, at a strategic level, to try to generate possible solutions, which could be suggested to the Health Service. Observational work could also be used to further investigate the patient–professional interaction. These possibilities are a little out of the scope of this thesis's primary aims.

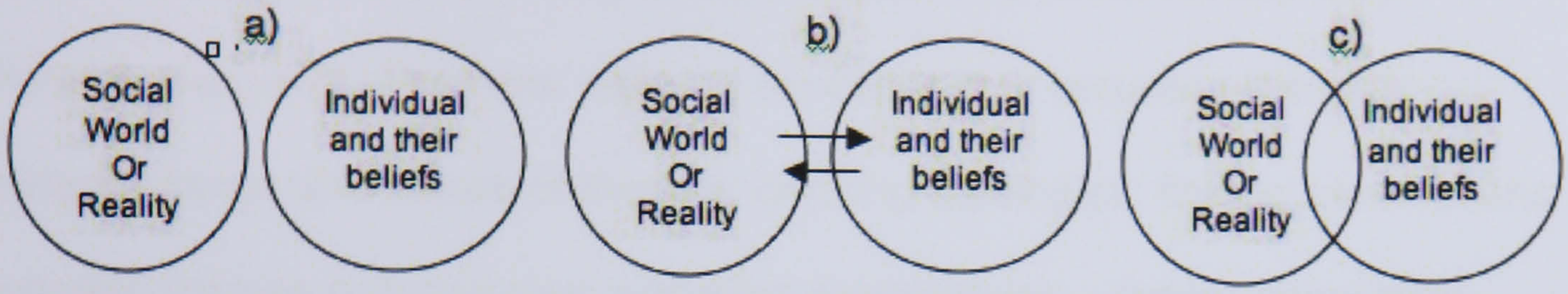
4.1.3 Ontology and epistemology

In qualitative research, the nature of the study and the analysis of the data gathered tend to be influenced by the researcher's ontological and epistemological stance and in the next few paragraphs I will outline mine.

Ontologically there are two extremes of viewpoint, realism and idealism. Realism purports that the social world exists independent to conscious thought or action and that there is no interaction between the two (Figure 4-1). Idealism at the other end of the spectrum suggests that the social world cannot be separated from conscious thought or action and is wholly dependent on it for its existence. Between these two extremes lie a number of moderate stances one of which is subtle realism.

Subtle realism recognises the interaction between the social world and conscious thought and acknowledges the somewhat symbiotic relationship between the two. This would seem intuitively true for the Health Service and the individuals practicing or being treated within it. I have, therefore, adopted subtle realism with respect to my qualitative data set.

Figure 4-1 - Ontological positions a) Realism b) Subtle Realism c) Idealism



Epistemologically there are again two extremes, positivism and interpretivism. Positivism asserts that the social world is unaffected by the researcher and the opposite is true for interpretivism. In my data set, the researcher and the subject will interact and impact on each other. This must be acknowledged and attempts made to minimise it, thereby taking an interpretive stance. The risk of interpretivism becoming interpretivism of convenience is tempered by the use of an iterative and inductive approach. In summary, the stance for this project is subtle realism and interpretivism. I acknowledge that the fact I am a clinician, researcher and sufferer of this condition will impact on the data and its interpretation to some extent, although I would hope that these different viewpoints will give added insight.

4.1.4 Qualitative analysis

Many different terms are used interchangeably to describe the broad process of qualitative analysis. The key stages (Burgess and Bryman, 1994) of qualitative analysis do not always occur in strict sequence nor are they mutually exclusive. They are: defining concepts from recurring themes; mapping range and nature of themes; creating typologies; finding associations between themes or typologies; providing explanations – theory generation.

The initial part of a qualitative analysis is the coding of the data (Section 4.1.6) with labels appropriate to the recurring themes. Coding is where the researcher looks at the data and separates it into concepts, assigning relevant phrases to concepts. Coding can take many different forms and the different forms are not mutually exclusive nor distinctly separate, they can occur synergistically or simultaneously. The coding is used to allocate data to categories or subcategories to allow the researcher to interpret the meanings of these different concepts and identify/analyse typologies or relationships between them.

The coding and typologies are utilised to assemble theory that can be tested against the data. There are various methods to formulate hypotheses from the coded data one of the more commonly used is the constant comparative method (Section 4.1.5) (Glaser, 1965). To stop the data from being too unwieldy and disorganised and to facilitate comparative analysis, a framework (Ritchie and Lewis, 2003) can be used to order the data by theme and by

subject (Section 4.1.6). This is the approach I have used for all qualitative data within this thesis.

4.1.5 Constant comparative method

As is commonplace in qualitative research a non-probabilistic sample is taken for the constant comparative method; this sample is made on the basis that it should provide relevant data for the research, not that it should be statistically representative. Sampling continues throughout the study until data saturation occurs which is when the collection process generates no new data and no new themes are being generated by the analysis. Analysis of the data is concurrent with the collection and informs the sampling process, in that the sample may be modified to search out further data, this is termed theoretical sampling. The simultaneous analysis of the data and its collection is termed the "constant comparative method" (Glaser, 1965).

Constant comparative method in its "pure" form is described in four stages (Glaser, 1965): comparing incidents applicable to each category, integrating categories and their properties, delimiting the theory and writing the theory. As an example, a category of professional perceptions of TMD patients emerged from the data set in study A in this thesis. As more data is analysed and coded into that category it is compared to the other data already present in that category to build an overall theoretical property for that category. In this case it might be negativity. This may mean developing a sub-category of negativity where the reasons behind this can be explored. As more theory takes form with more data gathered these categories would become delimited

by exhaustion, saturation and researcher amalgamation. The delimited coded saturated data means that the researcher can then assemble the theory.

With the qualitative data in this thesis, I have utilised both inductive and deductive techniques with the data. This is because I feel it is extremely difficult to maintain absolute separation from the data and it may be possible to overlook some of the richness of it if purely inductive approaches are applied. This obviously has to be tempered by constant rechecking, facilitated by the use of frameworks, of any deductive hypotheses against the data to ensure no "forcing" occurs. Theoretical sensitivity has a large bearing on this process.

Theoretical sensitivity is the ability to appreciate the nuances of meaning within the data. Strauss and Corbin (Strauss and Corbin, 1990) suggested that theoretical sensitivity consists of the following: insight; the ability to impart meaning to the data being analysed; a degree of comprehension of the data and the ability to sieve the pertinent data from that which isn't. Obviously theoretical sensitivity must be developed and this can be done through previous reading of the literature surrounding the subject, professional experience, personal experience, or the analytic process. With the first three of these there are potential pitfalls, for example; bias from the literature, blinding from years of experience to the "obvious", or assuming that everyone's experience is the same as yours. Developing theoretical sensitivity from the analytical process is more reliable as we gain insight and this insight triggers another hopefully setting in motion a cascade, encouraging even

closer examination of the data. It is developed from the analytic process by constant questioning, comparisons between and deliberation of the data.

Given my experience as sufferer and clinician I was exceedingly careful to develop theoretical sensitivity from the data, questioning and re-questioning the developing theory and I only utilised the literature once theory had been developed. In addition to this, I have tried to present the data from a three-point perspective: researcher, clinician and sufferer.

4.1.6 Coding the data

I utilised the three main forms of coding, as defined by Strauss and Corbin, (Strauss and Corbin, 1990): open, axial and selective. Open coding is an initial categorizing, naming and organisation of the phenomena that are being studied. The actual labelling of categories can be taken from the text or the researcher can create them; the important thing is that they are broad enough to allow sub categorisation. It is possible to open code by line, sentence, paragraph or document, bringing out the major concept/theme from that piece of data. Doing line by line coding will be the most generative and document coding will bring out the overriding theme of the document with the researcher having to return to the data to more specifically analyse it. Line by line coding was utilised for all of the qualitative data within this thesis. From the data in the thesis it is possible to provide a simple worked example of open coding for the category of treatment (Figure 4-2).

Figure 4-2 Example of open coding. Excerpt from transcription (top).

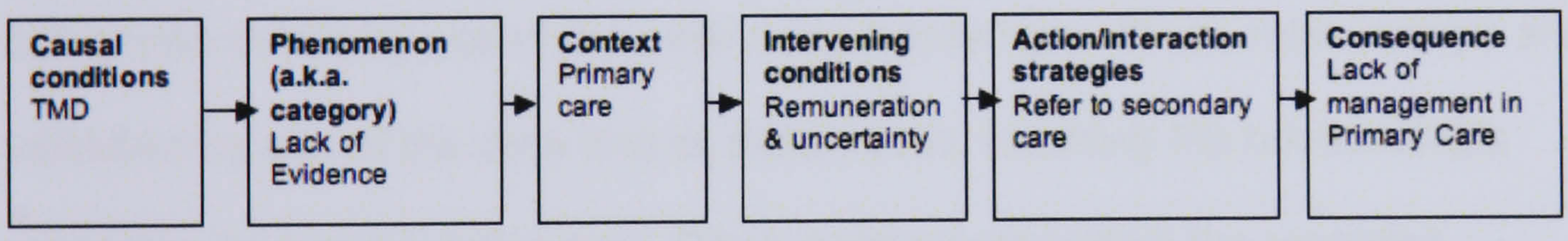
Open codes (bottom)

"If you embark upon a whole variety of different treatments none of which frankly have very much in the way of evidence based to support their techniques, in my opinion you are reinforcing in the patient's mind that they do have a serious condition that is continuing to give them problems but that you are just unable to treat it. Now the alternative approach, in my opinion, as I said, is to make sure that they understand that it is a chronic condition, it is an acute relapsing condition, it is a condition that tends to come back at times of stress and that if they understand that they will not have an unrealistic expectation of what treatment may or may not do" (OMFS 4)

Category	Subcategory	Properties	Dimensional range
Treatment for TMD	Evidence for treatment	Quality	Poor-[?Excellent]
		Quantity	Scarce – [?abundant]

Axial Coding is "Data put back together in new ways after open coding by making new connections between categories" (Strauss and Corbin, 1990). This is performed by the use of a paradigm, which is illustrated below with a worked example from the thesis's data (Figure 4-3)

Figure 4-3 – Paradigm (in bold) for use with Axial Coding (in normal).



There are several processes occurring when axial coding is used. The researcher can provisionally relate subcategories to categories by statements about the nature of these relationships. They can then verify these relationships by use of the paradigm and you can develop the properties of categories. Finally, they can explore the diversity of the phenomena (Strauss and Corbin, 1990). These processes are achieved by a constant flux between inductive and deductive thinking, for example in Figure 4-3 you might propose

(*deductive*), that the dentists were unwilling as a group to start treatment (*Consequence)* on TMD (*Causal condition*) patients because of a lack of evidence (*Phenomenon*) but you would then need to go back to the data to check (*inductive*), this hypothesis which would be verified by multiple occurrences in the data. The deductive statement must be supported by the data, it cannot stand on its own but it is very useful to make these deductive hypothesises to give depth to and develop a new angle on the data.

Selective coding is the process of integrating all of your previous analysis and data collection. It has a more abstract nature than axial coding. During selective coding "you are trying to develop a picture of reality that is conceptual, comprehensible and grounded" (Strauss and Corbin, 1990). It involves building a story line that is a descriptive piece of writing about the central phenomenon (category/theme) of the study and relating the sub-categories to this by use of the axial coding paradigm. These relationships are validated by use of the data and its dimensions, resulting the relationship's properties becoming delineated. Often during axial coding the repeated relationships between properties and dimensions of categories become evident and selective coding can be started at this point.

The theory developed must be grounded i.e. validated against the data. Often small numbers of cases may not fit the theory. This can be for a number of reasons: state of transition, case lying in the middle of the spectrum not representing either extremity well etc. In any such case the researcher should

explore the reason(s) behind this thus adding conceptual density to the analysis.

The coding that takes places allows for a methodical sifting, charting and sorting of data into well-defined categories/themes, which can then be used as the columns for the framework, with the individuals as the rows. Once the framework is set out, through the coding process, it can be applied to the data and charting can begin. Either data can be "cut and pasted" verbatim into the framework in the most appropriate category or it can be summarised and referenced in the appropriate categories.

Within the frameworks constructed for this thesis, I have chosen to cut and paste quotes verbatim into the framework and provide a summary of the data in the adjacent column. I believe this is advantageous, as the summary gives an instant link back to the data and the quotations incorporated in the framework reiterate the majority of the evidence in full, so that it can be questioned once again.

Charting of data into the framework can either be approached by case, or by theme, i.e. each individual respondent can be examined and have separate frameworks (case by case), or all respondents can be examined and placed in the same framework (thematic). Within my analysis both case-by-case and thematic chartings occurred allowing, within a spreadsheet, rapid sorting to permit questions to be asked of the data.

Once all the data has been placed into the framework, the researcher can then scrutinize the tables (framework), and develop theory and relationships between themes, essentially further axial and selective coding. Through this process patterns that have emerged between themes during the initial phases of coding can be explored further through the use of the framework, which presents the data in an orderly and clear fashion. A worked example of one of the frameworks from the thesis is shown in Figure 4-4.

Figure 4-4 Excerpt from transcript (top) and coding with excerpt from framework (bottom)

Interviewer: If I said to you I'll give you carte blanche or a magic wand to improve TMD. What would be your panacea? What would you do?
Interviewee: If you said if I had a magic wand to do things. I would like to invent some new tests, which give me objective evidence. Within TMJ there will be a family of disorders. There won't just be one, right. And we are messing them all up, right. And so we've got a mish mash. I would like objective evidence to try and unpick these so I could actually say you belong to Family B and you belong to Family C and Family D. Whereas we haven't got that now. So we're really ... we really are practising 16th Century medicine on TMJs. We're nowhere near the 20th Century. The other thing I'd say is that I would try to sell to the world the idea that ... of explaining to people the mechanisms involved. I'd like to know ... you know, the mechanisms I've described to you are the ones I've interpreted out of the data, I'm not sure that my interpretations are necessarily ... absolutely correct, they might be there or thereabouts, but they're not absolutely correct. It would be nice to have a firm scientific base of the mechanisms so you could explain to people and you could reassure them. And I think a lot can be done with further learning.

Area	Type	Code 1.8 Panacea	1.8Q Panacea Quotes
S	AACOMS	12	Would like new evidence and the new tests to create it. **"We are really practicing 16th Century medicine on TMJs. We're nowhere near the 20th century (6)".** Feels that we aren't unpicking the family of disorders that comprise TMD. So wants evidence to discover mechanism and confirm it and then work on diagnostic sub classification, which could allow us to educate the profession and reassure pt more effectively. *We do actually have the RDC to split TMD into sub classifications though.*	If you said if I had a magic wand to do things. I would like to invent some new tests, which give me objective evidence. Within TMJ there will be a family of disorders. There won't just be one, right. And we are missing them all up, right. And so we've got a mish mash. I would like objective evidence to try and unpick these so I could actually say you belong to Family B and you belong to Family C and Family D. Whereas we haven't got that now. So we're really ... we really are practicing 16th Century medicine on TMJs. We're nowhere near the 20th Century. The other thing I'd say is that I would try to sell to the world the idea that ... of explaining to people the mechanisms involved. I'd like to know ... you know, the mechanisms I've described to you are the ones I've interpreted out of the data, I'm not sure that my interpretations are necessarily ... absolutely correct, they might be there or thereabouts, but they're not absolutely correct. It would be nice to have a firm scientific base of the mechanisms so you could explain to people and you could reassure them. And I think a lot can be done with further learning (6)

4.1.7 Validity

There is criticism that firstly qualitative research lacks reproducibility and secondly, that it is strongly subject to bias from both the researcher and the subject (Mays and Pope, 1995b). To ensure that bias does not creep into qualitative research this same paper suggests that, as with quantitative research, there should be, "systematic and self-conscious research design, data collection, interpretation and communication". This obviously has to include careful selection of an appropriate interviewer as it is important that this person has no hobbyhorse in relation to the subject matter being examined or they may unduly influence the data. I have recognised and stated my position and have noted the potential bias that may bring. In recognising it I have reflected upon it and attempted to minimise it.

Further to the concern of influence, it must be borne in mind that the interviewer has to be appropriate to the subject matter and interviewees. For example it may be inadvisable to have the clinician who is undertaking the patient's care asking the patient about their perceptions of clinical practice as they will undoubtedly hold back some of the more complex or sensitive conceptions they have. With this in mind none of the patients interviewed in this study were under my care nor was I involved in their care.

There is also a risk of bias creeping into the final published paper. Mays and Pope (Mays and Pope, 1995b), quite rightly point out that it is very difficult to present the qualitative data due to its volume but suggest that it is possible to compile a quantitative summary of the results or represent extracted passages from the interview with a commentary of how the researcher has interpreted them. To achieve reliability it is suggested (Mays and Pope, 1995b) to organise review of the transcripts by independent qualitative researchers and compare the observations.

All of the data in this thesis was examined independently by one of the supervisors (Dr Cath Exley) to ensure the theory generated from it was representative of the data and valid. Areas of disagreement were minor and rare. They mainly related to the names used for themes or in coding and these were changed through negotiation between the two researchers. All of the methods and presentation of data are accordance with the U.K. Governmental recommendations for quality in Qualitative research (Spencer et al., 2003)

4.2 Professional interviews (Study A) method

The purpose of these interviews was to examine the reported practice and rationale of different members of the dental profession in managing TMD and secondly to identify any pertinent items for our topic guide to investigate the patient experience of the condition (Study C).

4.2.1 Sample

The purposive criterion based sample comprised both primary and secondary care dental practitioners. The sample was divided into practitioners from the north and from the south of the United Kingdom with York being the dividing city, to take into account any differences in practice as a result of socio-geographical influences (Doran et al., 2006). We interviewed individuals distant from academic institutions as well as some from within them to ensure a breadth of views. Table 4-1 shows the identification method, the inclusion criteria and numbers included of each type of practitioner in the sample. Experience within the research team in a similar study of professionals (McColl et al., 1999) suggested that approximately twenty interviews would be necessary for saturation; this was supported in the literature (Crabtree and Miller, 1999). In reality saturation occurred with eighteen.

Table 4-1 – Sample Characteristics of Study A

Primary or Secondary care	Type of Practitioner	Identification and Selection criteria	North	South	Total
Primary	**New General Dental Practitioner (NGDP)**	General Dental Practitioners (GDP) less than five years qualified at the time of interview and no further accredited postgraduate qualification were identified from the General Dental Council's (GDC) register	1	1	2
	Experienced GDP (EGDP)	GDPs greater than five years qualified with or without further qualifications were identified from the GDC register	1	1	2
	Special interest GDP (SIGDP)	GDPs were identified from the membership of the British Society for Occlusal Studies	2	0	2
				Total	6
Secondary	**Oral medicine (OM)**	Consultants in Oral Medicine were identified from the British Society for Oral Medicine's register	1	1	2
	Oral and Maxillofacial Surgery (OMFS)	NHS and Academic consultants. Identified from the British Association of Oral and Maxillofacial Surgery's register.	5 (2Ac, 3NHS)	2 (1Ac, 1NHS)	7
	Restorative dentistry (RD)	NHS and Academic consultants were identified from the Association of Consultants and Specialists in Restorative Dentistry register	2	1	3
				Total	12
				Cumulative total	18

Ac: Academic

4.2.2 Method

Once the sample was identified dental practitioners were invited to take part in the interviews by a standard letter with accompanying reply and consent forms, and an information sheet (Appendix 1, Section 8.1.1). This was posted to their listed address on the appropriate register. The reply form had an option to refuse and to stop any further contact to be made. If no response

was received within two weeks they were emailed and finally a phone-call was used to follow-up if there was still no response. If the offer was declined the next individual alphabetically that fitted the criteria (Table 4-1) was contacted. Twenty-two individuals declined from a total of forty-two contacted. The topic guide (Appendix 1, Section 8.1.1) was not given to any participant prior to their interview.

The topic guide was not a series of questions to be posed, but a series of areas that I wished to cover and these were presented to the interviewees in a variety of non-leading questions; some suggestions for these were included on the topic guide for ease of reference. The structure of the topic guide was used in a flexible manner and issues developing out of sequence through the interviews were probed and clarified as and when they arose. The topic guide, in those cases, helped ensure a full reporting of all areas. Where new recurrent issues arose during interviews or analysis, appropriate modifications were made to the topic guide. These are shown in italics in Appendix 1.

The in-depth interviews took place in a setting of the interviewees' choice, and at a convenient time for them. All distractions were minimised for an hour, although most interviews took between twenty five to thirty minutes and I conducted all interviews after appropriate extensive training. The interviews were digitally recorded and transcribed verbatim by a transcription company

(Typefast 2000[6]). I then checked the transcriptions for accuracy against the original recordings.

A grant was obtained from the Newcastle Healthcare Charity to cover the general dental practitioners reimbursement for their time at the British Dental Association guild rate £74/hr. Ethics approval was granted from the Eastern Multi-centre research Ethics Committee (MREC 04/5/031).

4.2.3 Analysis

Two of the research team (Dr Cath Exley and myself) studied the data independently and coded it appropriately. This coding was then discussed and a framework (Ritchie and Lewis, 2003) was agreed to help organise the data. An inductive and deductive iterative approach to the analysis occurred concurrent to the data collection. The data collection and analysis continued until saturation occurred (n=18).

[6] http://www.typefast2000.co.uk

4.3 Patient interviews (Studies B & C) method

4.3.1 Background

The first study involving patients, study B, aimed to triangulate data from a study using pain diaries, thereby identifying a review and reference period to be used when asking questions about TMD. The review period is the time taken for a clinical difference in the patient's condition to be measurable. The reference period relates to the phrasing of questions for patients. Specifically, it is the period, over which a patient is asked to reflect in the question (e.g. *over the past month* have you had problems with…?). Study B was part of the wider scope of the project to create a patient based outcome measure for TMD (Section 1) but was not initially conceived as forming part of this thesis other than informing the topic guide for study C. However, on analysis it was clear that there was an emergent nascent phenomenon that was not part of the study's original aim. The research team recognised this, but also recognised the need for further analysis and additional data to explore it in more depth.

The data associated with this phenomenon (Section 5.4.2) was presented to me for reanalysis when I was analysing the professional data (Study A). It was immediately apparent that there were complementary themes emerging with the professionals' reports. Once the professional data were analysed, the theory delimited and written up I reanalysed the whole of data set B from the

perspective of the theory emerging. The original framework for dataset B was not provided and I worked from un-coded, non-annotated original transcripts.

This re-analysis led to a theory emerging from the phenomenon but it could not be fully substantiated from study B's data set, which had been collected for a different purpose. The aim of study C was therefore modified from the original (comparing patient and professional perspectives and identifying any new items for the outcome measure) to include investigation of the emergent theory from study B. This was made the primary aim of study C as the emergent theory appeared to have implications for the successful management of TMD. It appeared to explain some of the mediation between health and illness in TMD and would therefore add a greater depth to our understanding of the condition and its response to treatment. It would therefore have bearing on the application of the outcome measure in its eventual validation.

In the following sections I will outline the samples and analyses for both studies B and C identifying the differences between them and the reasons for further investigating the theory.

4.3.2 Study B – Discernment of the reference and review period

For this study the interviews and initial analysis were carried out by another research team (Dr M.A.Moufti, Prof J.G.Steele and Mrs J.Smith) (Moufti, 2007). What follows is a description of the sample and then a description of the two differing modes of analysis used firstly by the other team and then lastly by myself.

Sample

A purposive critical case sample was taken consisting of secondary care patients with TMD. All of the patients had undergone treatment for at least three months and reported greater than a fifty percent improvement in their pain intensity since the start of treatment, measured by a Visual Analogue Scale. The reason for sampling improvers only was that the aim was to triangulate the reference and review periods for change in the condition with the pain diary data obtained from a separate clinical trial. The sample attempted to replicate the recognised female to male ratio of TMD (7:1) (Gray et al., 1994), however, due to difficulties recruiting patients by gender, a ratio of 9:1 was achieved. Twelve patients were approached and ten agreed to participate. The sample characteristics are shown in Table 4-2.

Table 4-2 - Characteristics of the sample in Study B

Pt Number	Gender	Age	Diagnosis*	Main complaint of condition
1	Female	65	Myofascial pain (MFP), Disc displacement with reduction (DDR), Arthralgia	Pain and clicking
2	Female	35	MFP, Osteoarthritis	Pain
3	Female	59	Osteoarthritis	Pain
4	Female	37	Disc displacement without reduction, Arthralgia	Pain and clicking
5	Female	52	MFP, Arthralgia	Pain
6	Female	54	MFP, DDR	Pain and clicking
7	Female	34	DDR	Clicking
8	Female	47	MFP	Pain
9	Female	33	MFP	Pain
10	Male	38	MFP	Pain

All patients had had >3 months in treatment

*Diagnosis made using criteria derived from Research Diagnostic Criteria (Dworkin and Le Resche, 1992). See Appendix 2, Section 8.2

Method

Once the sample was identified patients were invited to participate by standard letter and accompanying information sheet. If they were willing to take part in the interview process informed consent was obtained by the interviewer. The interviews were conducted by an experienced and trained interviewer (Mrs Jill Smith) who was otherwise uninvolved in the study or in the care of these patients. The interviews took place in a quiet office in the Dental Hospital, at a time convenient for the patient and lasted on average about 25 minutes.

A topic guide was utilised to ensure coverage of the material required. Analysis occurred alongside collection so as to inform the topic guide, however only minor modifications were found to be necessary. All interviews were recorded electronically and transcribed verbatim. Once transcribed and checked for accuracy the electronic copies were stored, annonymised and password protected until completion of the student's higher degree.

Ethical approval was gained from the Local Research and Ethics committee for the study (Newcastle and North Tyneside Ref 2003/83). At the end of the interview patients were offered reimbursement of any reasonable expenses occurred in attending the interview but none requested any.

Analysis

Initial analysis was iterative and was conducted by the PhD student (Dr M.A.Moufti). This produced a Framework that was verified by an independent researcher, one of the student's supervisors (Professor Jimmy Steele). This framework was then utilised to delimit and define the theory in relation to the reference and review periods. The analysis identified four themes that the researchers had thought might be pertinent and a fifth that was unanticipated. It was this fifth theme, the interaction between the care pathway and the psychosocial effects that the patient experienced, that caught my attention when presented and it seemed to complement themes emerging in the professional data (study A).

As stated, this fifth theme was unexpected and incidental to the main aim of this study. It was, therefore, unexplored within the original analysis and the data required complete reanalysis to further delineate this fifth theme. My secondary analysis of the data was conducted with the un-coded, non-annotated transcripts. The only grounding I had in the data previous to analysing it were the factors the other student had presented to us (Section 5.4.2) as part of this fifth theme. These helped inform my new framework as I re-coded the data. I conducted an inductive and deductive iterative analysis of the data reapplying the data multiple times to the emerging theory and refining the theory in line with the data. Each refinement of the theory led to a reanalysis of each patient in relation to it and a re-plotting of their data onto the theory.

Critique of study B

This critique is based around the suitability of study B to confirm the emergent theory from my secondary analysis of its data. The study was appropriate for, and achieved its main aim, the triangulation of the pain diaries and therefore the determination of the reference and review period.

In relation to the emergent theory from it, the sampling was inappropriate. A critical case purposive sample was used and therefore the study only included the improver's perspective, negating therefore, those non-improvers with chronic TMD whose story may be very different. Sampling did not continue to saturation for the emergent theory and therefore there may be differing aspects to the theory that were not accounted for. The female to male ratio was different from the clinical epidemiology of the condition and important perspectives from men may have been missed.

The aims of study C were modified to include a thorough exploration of the emergent theory from study B. Its sample and topic guide were adjusted to account for the theory and the flaws of the sample for study B.

4.3.3 Study C – Investigation of emergent theory and identification of new items

This study's primary purpose was to further investigate the emergent theory from the secondary reanalysis of study B. This emergent theory suggested there was a common journey which patients with TMD travelled, eventually arriving in secondary care. This journey, it appeared, impacted on the patient, their condition and their daily social activities. The journey's map could not be fully substantiated from the data from study B for reasons previously discussed. Study C's method and sample therefore sought to address the shortcomings of the data from study B and also aimed to investigate any new items that might need to be added to the outcome measure; the study's secondary function.

Sample

The sample for this study was drawn on the basis of the selection criteria in Table 4-3. It was a purposive criterion based sample aimed at including males and females, differing sub-diagnoses of TMD and improvers and non-improvers. The sample was constructed to try and include individuals who may have had differing perspectives of the condition.

Table 4-3 - Selection criteria for sample for Study C

Criteria	Details	Notes
Sex	Male or Female	Attempt to at least replicate female to male ratio of presenting TMD patients (7:1) (Gray et al., 1994)
Diagnosis	Those who are suffering from pain e.g.: Myofascial pain and arthritides, and those who are suffering from clicking due to disc displacement	Diagnosis made using criteria derived from the Research Diagnostic Criteria (Dworkin and LeResche, 1992). Criteria included in Appendix 2
Time in treatment	Must have had ≥ 3 months in treatment	Must have exceeded the reference period
Symptoms	Improvers and Non-Improvers	Defined by VAS score of pain over last month compared to VAS score of the last week. >50% reduction between two scores defined as an improver

It is difficult to determine improvers and non-improvers in chronic pain and especially in TMD whose symptoms fluctuate from day to day. The VAS score was employed to guide the sampling process rather than be definitive.

The literature (Crabtree and Miller, 1999) suggested that twenty patients would be necessary for saturation, where no new ideas or themes were being expressed. From our completion of the professionals study (Study A) we felt that this was reasonable. Twenty-two individuals were approached to take part on differing consultation clinics, surgical and restorative and only two

individuals declined to participate due to lack of time. The sample was recruited over a five-month period of time to allow analysis to occur concurrently thereby informing further sampling and the topic guide. This long time frame reflects the labour intensive nature of the analysis and the need to be able to adjust the sample to further explore the developing theory. The sample characteristics are shown in Table 4-4

Method

The sampling criteria were made available to the Consultants in Restorative Dentistry and Oral and Maxillofacial Surgery within the Dental Hospital to facilitate the identification of the sample. Once an individual was identified who fitted the sample they were approached with a standard information sheet (Appendix 1, Section 8.1.2) by one of attending clinicians or nurses, not the interviewer. If they were interested in participating they were offered an appointment at a time convenient for them and informed consent was obtained.

I conducted all of the interviews in a quiet office away from the clinical environment in the Dental Hospital. Interviews lasted between thirty and forty-five minutes and were digitally recorded and transcribed verbatim, the transcripts being checked by myself for accuracy. The in depth interviews utilised a flexible, evolving topic guide that had been informed by the data from studies B and A (Appendix 1, Section 8.1.2, items in italics were added during data collection and analysis). No participants were given the topic

guide and none of them had been involved in study B. Interviews and analysis continued until saturation, which occurred after nineteen interviews.

As this study followed on from study B, a substantial amendment application was made to the local research ethics committee (Newcastle and North Tyneside) under the auspices of study B's approval (2003/38). This was granted with amendments to the information sheet and consent form. Patients again were offered reimbursement of any reasonable expenses.

Table 4-4 - Sample characteristics of Study C

Pt number	Gender	Age	Diagnosis*	Main complaint of condition
1	Male	33	Myofascial pain (MFP), Disc displacement with reduction (DDR)	Pain and clicking
2	Female	18	MFP, DDR	Pain and clicking
3	Female	48	MFP	Pain
4	Male	48	MFP	Pain
5	Female	26	MFP	Pain
6	Female	36	MFP	Pain
7	Female	60	MFP	Pain
8	Female	47	MFP	Pain
9	Female	38	MFP	Pain
10	Female	23	MFP, DDR	Pain and clicking
11	Male	58	DDR	Clicking
12	Female	57	MFP	Pain
13	Female	52	MFP	Pain
14	Female	41	DDR	Clicking
15	Female	46	MFP	Pain
16	Female	47	DDR	Clicking
17	Female	24	DDR	Clicking
18	Male	42	MFP	Pain
19	Male	33	DDR, MFP	Pain and clicking

All patients had had >3 months in treatment

*Diagnosis made using criteria derived from Research Diagnostic Criteria (Dworkin and Le Resche, 1992). See Appendix 2, Section 8.2

Analysis

As the initial analysis of the data from the study began to form a new framework and further elucidate the developing theory from Study B, the data from study B were recoded in line with Study C's findings. All data from study B and C were combined into a singular framework to facilitate analysis of the new data. Two researchers working independently, Dr Cath Exley and myself, drew up the framework and then discussed and agreed a final version.

The constant comparative method (Glaser, 1965) was applied to the emerging map of the journey through care: for each individual patient in study B and C a new map was plotted with supporting quotes (key illustrative paths are shown in Appendix 3, Section 8.3). At each iteration of the map the other patients' maps were examined to identify any similarities or typologies. As further analysis occurred and changes appeared in the map as a result of new data the changes were checked against the whole of the data set B and C to ensure their validity. To facilitate this, all patients preceding the change were re-plotted onto the modified version to ensure its validity. Any deviant cases were noted and a provisional path plotted for them onto the map. Should further data emerge and support their provisional path they were returned to and the appropriate changes made to the map. Theoretical sensitivity was grounded in the data.

To achieve the secondary purpose of study C, data from both studies were also compared to the OHIP 49 items (Slade and Spencer, 1994b) (Table 8-1). A framework was designed using the forty-nine items of OHIP as a priori themes. Data was placed in these themes if there was qualitative textual evidence that the theme was relevant to the interviewee and that it had a frequent impact on their lives.

Whilst inputting data into the a priori themes any recurrent differences in the patients' phraseology were noted to allow for modification of the items in the eventual outcome measure. Any recurrent emergent themes that affected the patients' quality of life but which were not already covered were added to the framework and the patients' terminology was carefully considered to allow new items to be formulated from these recurrent emergent themes. Data collection and analysis continued until saturation (n=29, including 10 patients from study B). The results of this analysis is included in appendix 4 for information.

5 Data and Discussion

5.1 Background

Various specialists; predominantly oral surgeons, oral physicians (medics) and restorative dentists provide treatment for TMD, but some probably pass through non-dental specialities such as Rheumatology and Ear Nose and Throat Surgery. The treatment of TMD can be very time consuming for both patients and practitioners, particularly when the initial management is not effective, and its success seems to be highly variable and difficult to quantify.

There is no gold standard approach to TMD and treatment strategies vary from "conservative management", for example lifestyle changes, physiotherapy and simple pain relief, through to the provision of specially made splints, the use of specific medications, adjustments to the occlusion, complementary therapies and occasionally even surgery. Often the approach to treatment seems to include many of these approaches in a seemingly random order with no underlying strategy.

There is some reasonable evidence for the efficacy of different treatments, but often this is confusing and difficult to quantify. There has been an attempt to ascertain practitioners' attitude towards TMD utilising quantitative techniques (Just et al., 1991; Le Resche et al., 1993; Tegelberg et al., 2001). None of these studies (Just et al., 1991; Le Resche et al., 1993; Tegelberg et al.,

2001), however, explain the rationale behind management. The ideologies of dental professionals pertaining to TMD and their management have never been examined qualitatively.

TMD has been recognised as a chronic illness (Dworkin and Massoth, 1994) and therefore it is important to understand its psychosocial effects in order to understand the mediation between health and illness that can occur due to them. Studies in the literature have sought to quantify the level of psychosocial effects (Ahlberg et al., 2004; Steed, 1998) and their level of influence over management (Dworkin et al., 2002; Wexler and Steed, 1998). This has lead onto research demonstrating the possible efficacy of treatments, which target TMD's psychosocial effects, such as Cognitive Behavioural Therapy (Dworkin et al., 1994; Dworkin, 1997).

Quantification of psychosocial effects does not however explain or explore the intricate web of experiences, processes, emotions and social interactions behind the course of TMD, all of which will have bearing on treatment outcome. There is a need for qualitative research in this field to explore in more detail the psychosocial effects of TMD, which have been recognised as having an important role in the illness (Greene, 1995b).

In the following data and discussion, although the term "patient" is used, the individuals reporting their experiences in studies B and C are only patients within the context of clinical care. Out of clinical care they are individuals

suffering a chronic illness ("sufferers") that is exerting effects on their day-to-day living. The term "patient" is used simply for clarity within the text.

5.2 "Managing TMD is a black art" – The professional data (Study A)

Objective – To ascertain the ideologies behind, and rationale involved in, the management of TMD by dental professionals and to link this to the relevant patient experiences (from studies B and C).

5.2.1 Introduction

From the qualitative analysis two major common themes emerged. These were:

- Professional perceptions of TMD patients
- Intervention rationale and success

Both of these are reported in the following discussion and Table 5-1 gives the meanings for the acronyms used in referring to the speciality of the practitioner.

Quotations used throughout the discussion of the data are representative of the recurring themes and are used to support the theory being discussed. In parenthesis at the end of each quotation are the practice of the practitioner,

for example oral medicine specialists, and a number indicating the individual's study reference. Or, in the case of the patients interviewed, just their patient number in the study and the study they participated in, for example Pt 1B is patient number one in study B.

Table 5-1 - Acronym meanings for Study A

Primary or Secondary Care	Acronym	Speciality
Primary	EGDP	Experienced general dental practitioner (>5yrs qualified)
	NGDP	"New" general dental practitioner (<5yrs qualified)
	SIGDP	Special interest general dental practitioner (has interest in TMD)
Secondary	OMFS	Oral and maxillofacial surgeon
	OM	Oral medicine specialist
	RD	Restorative dentistry specialist

In the discussion of the professionals' perceptions I have, when possible, highlighted any similarities and differences between their report and the patients' (Studies B and C) reports. This adds depth to the analysis and discussion. Patient quotations are denoted by the acronym "Pt" in parenthesis following the quotation.

5.2.2 Professional perceptions of TMD patients

The perceptions theme was wide ranging and three sub-themes emerged:

- Perceived aetiology of the disorder
- Negative perceptions of the patients and their effects on management
- Perceived problems patients suffer

Perceived aetiology

My data reflect the uncertainty in the literature over TMD's aetiology; there is a diversity of reported perceived aetiology. Agreement between the professionals suggested the common belief was that there was a large element of bruxism, stress, distress and anxiety involved in the aetiology of these conditions. There is, however, very little support in the literature for any of these as a singular causative factor (Levitt and McKinney, 1994; Okeson, 2003; Rudy et al., 1995).

Alongside these more commonly accepted perceptions, other more idiosyncratic possible co-factors were also given such as *"...telephone holding in strange ways."* (OMFS 3), *"...resting hand on one side of head"* (RD 2), *"...sleeping position"* (SIGDP 4). These were not suggested as the sole cause, but as behaviours or habits that individual practitioners had noted in patients they had seen who suffered from TMD. They highlight the ambiguity

and therefore difficulty in identifying in initiating and exacerbating factors for TMD.

The diversity in beliefs can be explained from the data in two ways. Firstly there is a generalised assertion that there is ambiguity over what actually causes TMD. Leading on from this there is a suggestion that it is difficult to understand the mechanism of how TMD initiates and propagates and that uncertainty impacts on explanations to the patient about their complaint.

> *"I think it can be quite a distressing condition but in turn I think distress can actually exacerbate or somebody would say, cause the condition. And I think that's the difficulty that underpins all this and that it's so controversial in my opinion. Because, you know, you could get signs and symptoms of Temporomandibular Joint Dysfunction from being distressed. Well symptoms can be quite distressing. So you get into this vicious circle of what causes what" (OMFS 3)*

Practitioners sought to explain the condition in the best way they could and therefore the more idiosyncratic co-factors were probably a result of their attempts to empathise with the patient and point out something that was understandable to them as a possible exacerbator. In the evidence based healthcare system we are asking our practitioners to try and provide (DoH, 1998), the uncertainty over the cause of TMD has concomitant effects on their

faith in diagnosis, which in turn will effect their management. This "fear factor" in primary care is shown up in later data from the interviews (Section 5.2.3).

The uncertainty over aetiology and the concomitant concern of misdiagnosis seemingly impacts on the patients. In the patients' reports it is apparent that they lack a clear explanation of what is wrong with them and why it has occurred. This experience is, in the main, limited to primary care.

> *"I used to complain to the dentist quite frequently when I 'd visited and I was really, really bad and I told her. And she said well it wasn't a problem for her" (Pt 5B)*

> *"It would be very helpful if the dentists [referring to primary care service] knew more about it as well because then he wouldn't have to send people up here [dental hospital] and stuff. It would be less worrying" (Pt 2C)*

Patients' uncertainty over their diagnosis, as the last quote illustrates, serves to heighten their concerns over the (serious) nature of their complaints. This heightened concern explains some of the perceived "neediness" of these patients in section 5.2.2.

Negative perceptions of the condition and their effects on management

From the data it seems that TMD is often perceived negatively; in both primary and secondary care, patients can often be regarded as difficult.

"Interviewer: Would you potentially be interested in being a practitioner with a specialist interest in TMD if the lab fees were incorporated into that?
Interviewee: No I don't think so because I think you'd probably end up getting quite a lot of patients with needing to see psychiatrists rather than dentists" (SIGDP 4)

"I think there is [are] sometimes patients who refuse to comply with the treatment you suggest and I think the ones that [pause] you have to be careful of the ones where the reason they're doing that is part of a kind of game issue. Psychological game thinking that they need that problem, they don't actually want to be cured because it's what they need to make their mark in life" (RD 8)

"Interviewer: Is there any reason why you might turn round and say to someone who appears to have TMD and say I don't really

want to treat you, I think really you'd be better served going straight to hospital?

Interviewee: Only those tricky patients who have always been tricky patients [interviewer- tricky?]… Tricky as in always been difficult to treat and never been able to particularly find out what was driving their problems. Whether it was the actual problems they were coming to see me about or whether another problem that was manifesting itself in a dental way." (EGDP 13)

This perceived difficulty with the "tricky" (EGDP 13) or heartsink patient and their management appears to colour the general perception of TMD and can result in fatalistic approaches towards managing TMD.

"I think the treatment of TMD is a very difficult subject to actually approach and unless you get a specialist who specifically likes the treatment of TMD problems, you tend not to get very far anyway"

(OM 11)

"TMD patients weren't particularly enjoyed. They weren't seen as core business by anybody…And I think consequently it's given quite short shrift" (RD 2)

Within the patients' reports there are cases demonstrating both the "short shrift" and fatalistic attitude towards TMD from some professionals.

> *"So I went to the oral surgeon … back to the oral surgeon who kind of dismissed the physio[therapist] and said that there was an operation I could have but really he doesn't recommend it because it's quite intricate and I could end up with facial palsy, and I wasn't having a lot of pain actually in my jaw. He didn't recommend it and he said what did I expect … oh no, he said welcome to old age, that was it. After I'd just had my 40th birthday which kind of wasn't great." (Pt 14C)*

Some patients even received explicit negative labelling due to the nature of their complaint.

> *"Well I felt terrible, especially when my GP refused to refer me anywhere and told me I was a timewaster who was just imagining it. And, you know, not to bother him anymore. And then I changed my GP because I was so incensed about this. And then [Consultant's name] more or less just said the same thing." (Pt 8C)*

This discreditation of the individual is based on either the perceived psychological element to TMD or in the case of those without a

diagnosis, their medically unexplained symptoms, their potential psychosomatism. The only other qualitative study in chronic orofacial pain has found similar instances of discreditation (Wolf, 2006). If the clinical "heartsink" nature of TMD was widely known to the general population it could drastically affect their presentation and management. They may become less likely to divulge the condition's psychosocial effects thereby making it increasingly difficult for the clinician to manage the complaint.

The reported perceived difficultly in successfully managing the condition led to a report of coercion of patients to report improvement so that could be discharged.

"Interviewer: How long do you leave them [the TMD patient] to see if they respond?

Interviewee: Well I think I'd leave them as long as they are happy to be left. I think all these things tend to be patient driven to be quite honest with you. The [pause] you know, the patients who do come in and are [pause] I think you can always convince TMJ[7] patients to a large extent that things are improving. Whether they are or not I don't know." (EGDP 13)

[7] TMJ actually stands for Temporomandibular joint but is often colloquially interchanged with the correct scientific acronym TMD

The preceding quote (EGDP 13) further illustrates the ambivalence towards TMD that underlies some of the primary and secondary care practitioners' reports. Practitioners can have a fatalistic attitude towards managing TMD and may not view it as a high priority; they can be inclined to avoid managing these sometimes-tricky patients. Other research into chronic illness (May et al., 2004) suggests that the "disposal" of the patient has a large bearing on the relationship between the patient and their care provider. If disposal, by referral or discharge most commonly, is not achievable the relationship deteriorates. It then becomes a relationship where the practitioner tries to contain the individual's expression of symptoms. It is clear that this is possible with TMD also and it may be this process of containment that leads to professional concentration on the biomedical aspects of TMD and patients dissatisfaction with the psychosocial aspects of the consultation.

In terms of consultation time TMD patients were felt to require intensive consultations in both primary and secondary care and were consequently perceived as being "needy" as illustrated by the quote below from an oral medicine specialist. Primary care practitioners particularly emphasised this time intensiveness, as the time spent was ill recompensed (Section 5.2.3).

> *"No I think that they (pause) occasionally you open a large can and sometimes it takes quite a long time to talk through"*
>
> *(EGDP 10)*

"Interviewer Do you have any private practice in TMD?

Interviewee [OM] No.

Interviewer If you did would your management of TMD differ at all from the NHS management?

Interviewee I don't think I would ever do private practice in TMD actually.

Interviewer Why is that?

Interviewee Because of the neediness of the patient and … well I maybe completely wrong but I get the impression that … well there can be quite demanding at best, but I think if they were a private patient then I think they might think there's a certain ownership. " (OM 5)

Dental primary care remuneration has been shown to influence the provision of care by general dental practitioners (Wright and Batchelor, 2002). In particular the balance of time against level of remuneration has been demonstrated as a key influence (McColl et al., 1999). The remuneration system at the time of this study did not pay general dental practitioners for the time they spent with a patient but instead recompensed them for the treatment

they provided; the old fee-per-item system, therefore if a procedure was more time consuming and ill-recompensed they earned less.

TMD patients, by their nature, often need time intensive consultations due to the intricacies of finding aggravators to the condition or even diagnosing the condition, as its presentation can be extremely varied. TMD patients may therefore not be appealing in primary care, firstly due to the practitioners' insecurity in the diagnosis (Section 5.2.3). Secondly, due to the perceived difficulty in making the diagnosis and finally, due to the difficulties with the remuneration for diagnosis and management be it time for history taking, counselling or for example fitting splints that might be required (Section 5.2.3). This may well account for the numbers of received referrals to secondary care for TMD, 10 per week in one study (O'Donovan et al., 2003) of which only 6% of the referral letters were felt to contain useful information about the patient's condition. These are large numbers of referrals per week for a condition, which is quoted as being symptomatic in 20-25% of the population with symptoms severe enough to warrant treatment in 3-4% (Gray et al., 1994).

With the changes in remuneration in the general dental services, whereby the general dental practitioners are salaried for the care they provide, the numbers of referrals to secondary care may change. However, one primary care practitioner remarked that referrals might increase with this change due to a cap on laboratory fees per month. He remarked that the general dental

practitioners might choose to refer to secondary care rather than use up their allotted funds on splints for TMD patients.

> *"It's not so much a problem for myself as Practice Owner but I think for the Associates ...and humans are humans. If you make more Laboratory [items] you take home less money. So I think that the chances of more referrals happening within the PDS system for TMD dysfunction is more likely. The only way that hospital services can stop that from happening is to suggest that if they're going to prescribe a splint they will be made in practice"* (EGDP 10)

Since the advent of the new dental contract (DoH, 2005b) three bands of patient charges have been set (Band 1, 2, and 3) and there is no need for approval before making a splint (Section 5.2.3). The lower soft splint falls into the highest band of treatment (Band 3) at £194 (DoH, 2007). This set cost, which is a great deal higher than previously, may now have bearing on the general dental practitioner's willingness to prescribe them for patients; they may choose to use them more as the time:profit ratio is now much larger or they may choose to use them less as they may feel patients will not pay such sums for what, to them, is a "gumshield". If patients refuse to pay this higher fee for a lower soft splint general dental practitioners may be forced into making more referrals to get the splint fabricated in the local dental hospital for free. There have already been concerns noted in letters and articles in

journals (BDJ, 2006a, b; Syed, 2006) over the deleterious effect of the contract on provision of dentistry within England but as yet, no data are available on its impact.

Perceived problems patients suffer due to TMD

Practitioners acknowledged some of the problems that TMD patients presented with. The most frequent practitioner perception was that pain was the over-riding concern for these patients. *"In the order of priority, pain is the most important as far as I can tell"* (OMFS 16). *"It's always pain they come about"* (SIGDP 17). They appreciated the magnitude of complaint that the patients reported, but didn't seem to give credence to the extreme level of the pain that might be experienced by the patient, as suggested by studies B and C.

There is some evidence in the literature that TMD patients have genetically coded high pain sensitivity (Diatchenko et al., 2005). This could explain the lack of insight from the practitioners; they are receiving reports of "headache-type pain" as symptom descriptors from TMD patients and perhaps interpreting this description as a minor level of discomfort due to their own experience of, and genetic coding for, pain. This semantic difficulty is highlighted in work done to assess the language used by patients to describe dentally related pain, (Smith, 2005), which shows that the language rarely

allows quantitative assessments of the pain to be made accurately. It would appear from the patients' data that it is not a language deficiency that causes this problem but possibly the formulaic nature of "history taking"[8] in the consultation process.

The patients interviewed in studies B and C often needed a large amount of time and prompting to describe their complaint in full. The professionals have already emphasised the time constraints they are under and therefore with a formulaic history they may skim over the important psychosocial effects the patients wish to report. In describing the pain that constituted a significant part of their complaint, the patients commonly used the suffix "-ache". Earache, headache, jaw ache, and toothache were amongst the most frequent descriptors used.

"Well it was my jaw and I was keep getting ear ache with it" (Pt 4C)

"Because I was getting a lot of headaches but very, very frequent headaches and I was quite concerned because, you know, you don't know what it is and they were quite sort of intense headaches. But always on one side of my head and always seemed to be around the temple area." (Pt 6C)

[8] Process of obtaining the details of a patient's complaint by relevant questioning

When the use of "-ache" was probed, something the professionals may not have the time nor the inclination to do, patients reported a more substantial level of pain than one would associate with the word "ache" which is "a dull persistent pain" (WordNet, 2007). The level of pain the patients intended to communicate was a more severe level of pain than just a background pain. This pain also radiated into various sites with the more common sites being the temple, the ear, the eye, the jaw and the neck.

> *"then I got this horrendous like jaw ache, you know... But it was so like from here and all the way down here, my neck, and it went round the ear and then behind my ear, right" (Pt 13C)*

The patients were however, if given adequate time and opportunity, able to quantify their pain verbally to a non-clinician (study B) and a clinician (study C) thus raising the question that perhaps more discourse and time is needed in a consultation to ascertain the magnitude of pain and its psychosocial effects.

Research examining the use of pain descriptive words in relation to chronic orofacial pain conditions has shown no discernable differences in those used by patients for TMD and those used for other common orofacial pain conditions (Vickers et al., 1998). Within that study the diagnostic criteria for the orofacial pain conditions were those set down by the IASP (Merskey and Bogduk, 1994) and all individuals had a multidisciplinary examination and

undertook the McGill pain questionnaire (Melzack, 1975) to help ensure diagnoses were as accurate as possible.

Vickers et al (1998) found that the most common words, throbbing, sharp, aching and intense, were used for atypical odontalgia, atypical facial pain and TMD. From a clinical perspective, this will lead to difficulties in gauging the level of discomfort and in obtaining a diagnosis. These researchers demonstrated TMD to have the most intense pain in the study, even higher than cancer or back pain, but the words patients used did not distinguish this as the case. This can then lead to misinterpretation by the professional.

A large amount of non-verbal communication occurred[9] when the individuals described their pain to me in the patient interviews. This form of communication could perhaps provide leads, within the consultation, for the clinician to follow thereby ascertaining the true magnitude of the pain and its effects. Unfortunately, experienced clinicians have been shown to be poor at rating patient's pain from non-verbal cues (Prkachin et al., 2001). Add to this our data demonstrating that the professionals can view TMD as difficult and time consuming and it implies a distinct possibility that these non-verbal clues may go unnoticed. Prkachin et al suggest that the "distancing" ability health professionals possess may blunt or turn off their ability to read the non-verbal cues of pain thereby hindering their interpretation of the patient's complaint.

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[9] Patients used emotive hand, face and body gestures for example Pt 13C shuddered, grimaced and began to cry during the description of her pain.

This all leaves the patient's report open to misinterpretation by the professional.

The practitioners' measurement/assessment of pain and its effects is further complicated and compounded by the problems of quantitatively and objectively measuring pain in TMD (Conti et al., 2001). If objective measurements are difficult, subjective patient based methods have proved somewhat more encouraging. Furthermore, incidental subjective measurements of quality of life in TMD patients have shown a decreased quality of life (Di Fabio, 1998; John et al., 2002a, 2007). Throughout our data set there is, however, little mention of the impact of TMD on the patient's day-to-day activities. This may again be due to a clinicians lacking personal experience of the condition and therefore the level of pain, or it may be due to way dentists think about the condition. It may even be due to patients' perceptions of what they think dentists want to know.

So why do the clinicians have a fascination with, and focus on pain rather than other more psychosocial aspects of the complaint? It could be suggested that most of dentists' initial training focuses on management of pathological processes that cause pain or discomfort. It may therefore be a lack of training, rather than a lack of interest, that prevents them from ascertaining the psychosocial effects of the condition from the patient.

"Well, for most of mine it's the actual pain itself rather than any functional disability." (OM 5)

"[What were the problems that you think, or you've experienced that patients with TMD have suffered from?] Pain in the face and pain in the muscles, pain in the jaw joints and occasional dental pain as well" (NGDP 1)

The patients, though, had important psychosocial effects to communicate to the clinician, which may have given insight into the level of discomfort they were experiencing.

"I just wanted to lie in bed all the time, I was just in so much pain, I didn't want to get out of bed" (Pt 2B)

"Well I couldn't stand the sight of food in the end because every time I ate something I was in this pain. And then the only way to manage that was by taking painkillers and then it became [pause] the painkillers weren't effective and I was taking way over the recommended dose and I was just a walking, you know, a bundle of pain. I couldn't sleep, I couldn't eat, it was just terrible" (Pt 8C)

Health professionals have been shown to miss psychosocial verbal cues in chronic illness previously (Ring et al., 2005). From the professional and patients' data it appears likely that this might also be the case in TMD perhaps again due to professional distancing or the perception that *"occasionally you open a large can and sometimes it takes quite a long time to talk through"* (EGDP 10). The patients interviewed in studies B and C repeatedly expressed dissatisfaction and frustration with some practitioners' ability to understand or listen to their complaints. This may account for the "neediness" that the professionals reported experience of (Section 5.2.2). The patients may have felt compelled to try and make the professional listen and understand their problem. The other contributor to their "neediness" was most likely their wish for a diagnosis (Section 5.3.3); they, *"just wanted to understand what was wrong"* (Pt 2C). This search for a diagnosis is common in most chronic illnesses as a part of a process of legitimisation of the illness (Borkan et al., 1995; Reid et al., 1991; Shaul, 1995; Taylor, 2005). The search often leads to further frustration, confusion and stress on the part of the sufferer, which is reported within the patients' data in this thesis.

> *"I went to the doctor who said there's no [organic] problem [causing the pain]. It started getting worse but he was insisting there was no problem…Meanwhile it was getting near to Christmas…and I was in that much …I went private in the end [because] my husband said "look you're not going to be like this over Christmas"" (Pt 12C)*

"Well frustrated because I knew something was wrong. My jaw and my teeth felt wrong and nothing was being done about it. …. First time I went [to new GDP], again mentioned something [about problem] to him, but nothing was done again. Eventually I kept pestering with just going for monthly check-ups… And eventually, I don't know if he was sick of me or what, but he took another cast of my bottom teeth" (Pt 1C)

The patients' data also suggest that in clinical encounters professionals may be adopting paternalistic decision-making, more reminiscent of the Parsonian Sick Role (Parsons, 1951), than a more shared approach to decision-making advocated by others (Charles et al., 1997). This may result in a lack of patient centred consultations.

"I saw him [Surgery consultant] privately at the [name] Hospital which he put the camera down [her pharynx], told me there was nothing in there, and all I got out of him was cut the cigarettes and stop drinking coke and that was me conclusion [in relation to TMD complaint]." (Pt 12C)

"I had faith in Dr [name of final consultant to see the pt] as he was the only person who listened to what I was saying…And this particular registrar [previous experience in secondary care],

which he was, came in, looked at my mouth, he said well nobody's bite's perfect. He said I think you're just grinding your teeth and you've got acute TMJD[10]. You either stop grinding your teeth or I'm going to have to send you to see a psychologist and even wire your jaw." (Pt 9B)

This paternalistic decision-making may be the result of the professionals' reported focus on the biomedical rather than a discussion of the psychosocial. They may accept that there is little they can do for the psychosocial effects and therefore paternalistically dictate that they will attempt to manage the biomedical. Without adequate information on the psychosocial effects, however, these attempts may be unsuccessful. Qualitative research with patients suffering from different types of chronic orofacial pain discovered similar difficulties with the consultation process: feelings of being distrusted, feelings of frustration at not being able to communicate the elusive pain to the clinician and towards the clinician for not listening (Wolf, 2006).

It is not uncommon for practitioners dealing with chronic illnesses to concentrate on the biomedical rather than the biopsychosocial (Hewlett et al., 2001; Rothwell et al., 1997). When this occurs, patients with chronic illnesses can find the biomedical aspects of the consultation to be thorough but the psychosocial aspects, which the TMD patients in this study appear to rate higher, wanting (Laerum et al., 2006). Laerum et al's research showed that

[10] Previous nomenclature for TMD.

patients wanted an explanation of their problem in addition to discussing the psychosocial aspects of it. In TMD we know that the professionals can find a diagnosis difficult to give (Section 5.2.2) and that they rarely address the psychosocial effects of the condition.

5.2.3 Interventions rationale and success

Before beginning to examine the data relevant to interventions, it must be noted that there was a key difference between the primary and secondary care practitioners at the time of interview. The primary care practitioners were remunerated on a fee-per-item basis of treatment whereas the secondary care practitioners were salaried. In addition to this, the majority of patients seen by secondary care practitioners would already been examined by one or more practitioners and may or may not have been given a diagnosis and treatment.

Within the data, there was a clear indication of the primary care practitioners' disenchantment with the fee scale for TMD treatment. Their reason can be split into two halves. Firstly, implicitly and explicitly they felt they were not compensated for the time required to counsel these patients properly. Compounding the difficulty with the fee for the examination was the lack of clarity over the fee for the commonest form of management, a lower soft splint (soft gum shield for the lower teeth). The fee scale itemised the most common

treatments general dental practitioners provided and gave a clear charge for the patient and idea of what the practitioner would receive, "fee-per-item". For more complex, costly or less common treatments the practitioner had to contact the funding body, The Dental Practice Board, and request "approval" for their treatment plan. If granted the Dental Practice Board would inform the practitioner of the price to charge the patient as well as the payment to the practitioner.

The lower soft splint was one of the "approval" items and the general dental practitioners felt that this was overly burdensome for something, which is seen as part of the initial management of TMD.

> *"It's the difficultly with having to write for approval… money comes down to it at the end of the day in General Practice and people need to know what they're taking on [the cost of a lower soft splint]….I can't understand why the GDS [general dental service] doesn't have a simple code for making a splint"* (EGDP 10)

Within primary care, the next choice of management after the soft splint was often a hard splint and there was again, no appropriate fee. All of this made counselling and initial management of TMD difficult, apparently due to cost implications, either because: the item was difficult to get priced; simply inappropriately priced; or its time intensity made it inappropriately priced.

> *"...A hard splint now, it's an item you can't get done on the NHS. There will be a fee for it but you can't get a lab who will make you one for a reasonable price. So you're stuck with, you generally have to offer it as a private thing because the lab fee would be more than the fee would be from the NHS."* (SIGDP 17)

The secondary care practitioners generally perceived that primary care should provide initial reversible therapy before referral. Initial reversible therapy commonly constituted of a combination of lower soft splint, counselling, analgesia and patient-administered physiotherapy/exercises. The secondary care practitioners frequently, however, did not have any understanding of primary care fee arrangements. There is therefore a disparity between secondary care's wishes and the primary care practitioners' ability to satisfy those wishes, due to the fee scale. This may have changed with the Government's plans for primary care dentistry although one practitioner speculated that these changes might worsen the situation and another suggested that the fees for splints should be removed altogether as some patients can't afford the treatment. At present the disharmony in primary and secondary care ownership of initial management of TMD may make it possible for a patient to end up without any appropriate initial management.

"I think that initially the, you know, patients who present to the general dental practitioner with some complicated stress overload, TMJ syndrome, should and could be diagnosed and treated within primary care. And the majority of those will get some help" (OMFS 6)

> *"I think all the sort of baseline [conservative] treatment that we do here [in secondary care] and the diagnostic process is not specialist treatment. I think all that could happen in primary care."* (RD 8)

The extent to which primary care practitioners were prepared to practice in TMD seemed limited by three factors: the fee scale, a lack of education/knowledge and fear of misdiagnosis.

> *"If someone's got a really chronic pain where they can't sleep, they can't eat. I might decide that maybe it's the best that they're seen by someone who knows what they're doing rather than someone who's just trying to guess" (NGDP 14)*

Primary care practitioners were concerned that due to the sometimes-atypical presentation of TMD that they may misdiagnose something more sinister as TMD. They therefore referred to secondary care as reassurance for the patient and themselves. This need for reassurance may stem from the paucity

of information on TMD the practitioners report they received during their undergraduate studies, a situation that was not just limited to the experienced practitioners. The combination of their lack of knowledge and fear of misdiagnosis seems to make referral more likely especially if faced by a patient who doesn't respond to initial reversible management.

> *"I'm always terrified that I try to do something and really they should be seen by doctors and have their symptoms investigated elsewhere" (SIGDP 4)*

Although primary care appeared concerned over misdiagnosis this appeared limited to misdiagnosing a potentially sinister condition as TMD. In the patients' data, however, there are reports of inappropriate irreversible interventions on the basis of an odontogenic misdiagnosis for TMD symptoms. This is something the primary care practitioners did not recognise as a problem but the interventions, which inevitably failed to address the problem, only served to heighten the patient's anxiety over the source of their complaint, in some cases worsening the complaint (Section 5.3.3).

> *"And he removed the tooth in the January and the problems didn't go away. And then I started to panic and thought God he's taken out the wrong tooth" (Pt 3C)*

"The first time I had pain with my teeth I had a root canal … they took the old filling out and the root canal. Anyway they tried to numb it and it just wouldn't numb. They just kept drilling and drilling and drilling. And in the end the root canal filling didn't work so I had the tooth extracted. And I had the pain in the bottom of my jaw on the left hand side and then it went to the top. And I had another filling up there and the root canal fell out again... And ever since then I've had facial pain. It's gone from side to side" (Pt 18C)

Primary care practitioner's lack of education with respect to TMD was also recognised within secondary care and was suggested as a key area to target to improve TMD treatment.

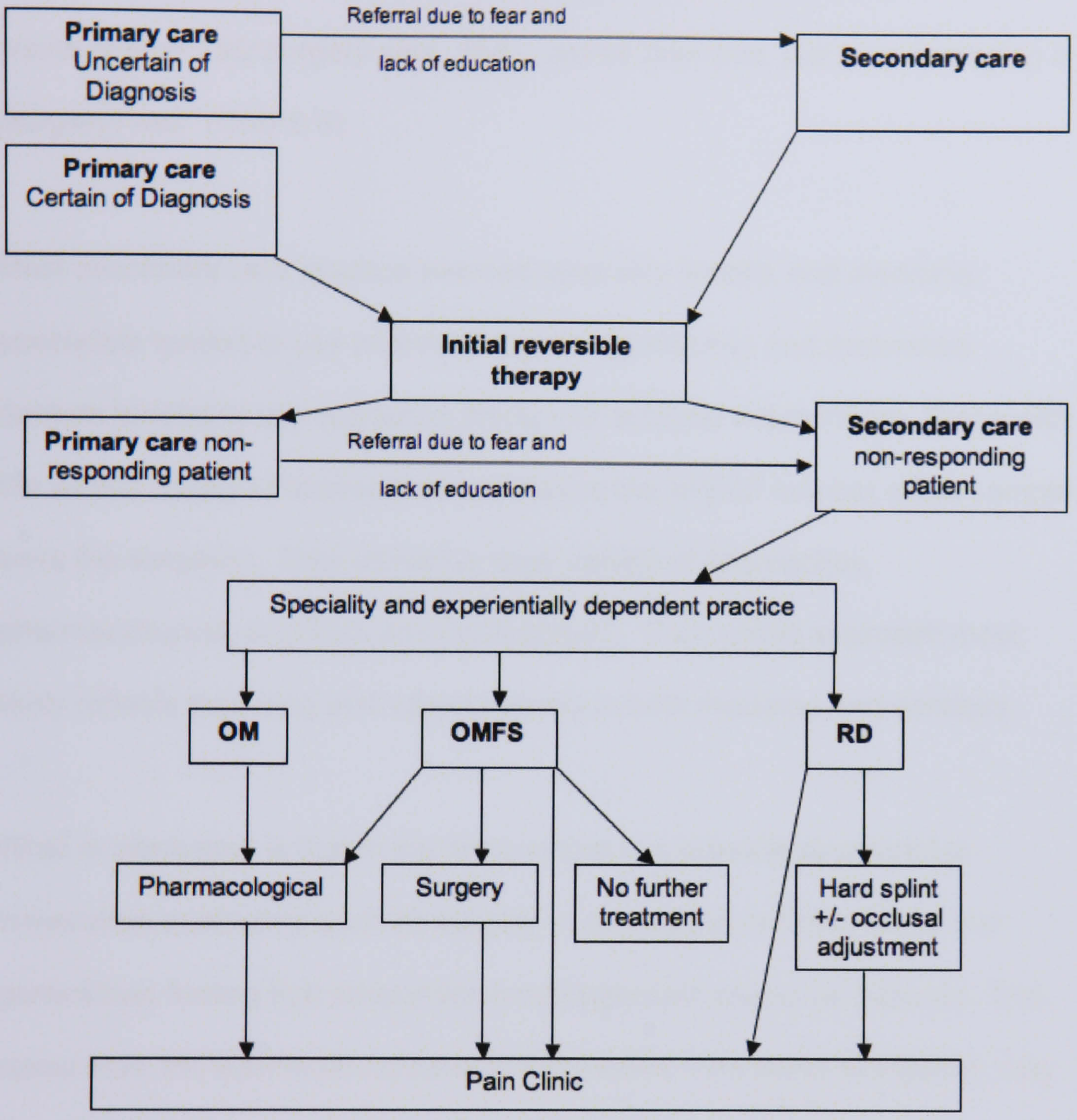
"You'd have to start with education. The equivalent of primary care. Practitioners who could be doing most of the first line treatment" (RD 8)

The lack of undergraduate education and postgraduate initiatives to improve the level of knowledge in TMD has recently been recognised in Europe and initiatives have been started in the Netherlands to help rectify the gap in knowledge and management (Steenks, 2007).

The primary care practitioners reported that they might try initial reversible therapy for TMD before referring to secondary care dependent on the certainty in their diagnosis. The primary care practitioners had a uniform approach to patients who failed to respond to reversible therapy; they tended to refer them to secondary care. This referral was influenced by their fear of misdiagnosis and level of knowledge to manage TMD. Once a patient was seen within secondary care there appeared to be a myriad of treatment modalities that were employed once initial reversible therapy had failed. Figure 5-1 outlines these possibilities by specialty.

Suitably trained general dental practitioners have been shown to be very successful at performing the initial management of TMD (Wassell et al., 2004) and it appears that general dental practitioners in my sample were exhibiting regret bias (Croskerry, 2002) that is: they are overestimating the probability of a more sinister or serious diagnosis and referring into secondary care to rule it out, as a "safety-net". This is a heuristic or "rule of thumb" and generally the usage of these increases in conditions of uncertainty (Hall, 2002). In this case the uncertainty is due to their lack of knowledge in relation to TMD and therefore they are uncertain in their ability to diagnose and manage the condition.

Figure 5-1 Flow chart representing the treatment decisions for primary and secondary practitioners for TMD patients.



Within secondary care the management pathway of the non-responder was dependent on the specialty of the practitioner. However in disregarding the specialty of the practitioner it becomes clear that the basis of secondary care

management was generally based upon pragmatism, anecdote or their experience during training, bad or otherwise. *"I base it on quite a lot on experience, quite a lot on common sense"* (RD 2). *"I then also worked with another two consultants who operated on quite a lot of TMJ patients …what a waste of time TMJ surgery was. But …worse than that, just how damaging it [surgery] was"* (OMFS 6).

Most secondary care practice seemed speciality limited, oral medicine specialists tended to use pharmacological approaches and restorative dentists tended to use appliance therapy or occlusal adjustments. Those with the widest variety of approaches and hence the largest number in the sample, were the surgeons. They utilised a large variety of approaches, pharmacological, cognitive and bio-feedback. Their varied approach most likely reflects their long and varied training in both medicine and dentistry.

What is interesting is that in the fields where it is possible to commit to irreversible treatments such as surgery or restorative dentistry there is a generalised feeling that conservative management should be pursued. This stems from the wish to do no harm to the patient. The worry of litigation may also play a role in pursuing conservative management but this is not mentioned in the data.

"There's very little good science in TMJ. There's a lot of witchcraft and there's a lot of opinion. And there are a lot of

these evangelical factions propagating dubious scientific theories.... The only thing that concerns me, as I say, is people that get irreversible interventions which ultimately are quite damaging. Also I'm concerned sometimes when I see how much patients are in pain from the witch doctors" (OMFS 6)

"What I would not want to do in these patients is to make them worse, and as I said before, followed up for long enough... most of these patients will actually improve with time. And what you do not want to do is to finish up with a patient who is in a worse situation after your treatment than you were before you started. There are always going to be patients you are going to fail with" (OMFS 7)

The surgeon's reluctance to engage in surgery for TMD is due to the flawed literature. It is fortunate that they are generally reticent toward committing individuals to surgery as some of the patients interviewed in studies B and C reported they would have considered it.

> *"Well the two major harms [of surgery], and the first goes back to the reassurance. The psychological harm that an individual's been through an operation with an expectation they were going to be cured and after the effects of the immediate surgery had worn off...they find they're back at square one or maybe even*

worse and because they're back at square one become more miserable about it, and because they're more miserable about it the symptoms get worse, either perceived as being worse from a psychological point of view or actually worse because, you know, the surgery's made things worse." (OMFS 9)

> *"I think I would have had to weigh the pros and cons of it [surgery] but I think I possibly would have gone ahead with it at the time. I mean it's hard to say now because it's quite a while since I've actually been in that pain"(Pt 10C)*

The one surgeon in the data who did no further therapy after reversible therapy failed did so on the basis that any further management might only serve to reinforce in the sufferer's mind that they have a serious condition. His rationale was that *"Reassurance…at the outset, done with confidence is as important as anything in the management of the condition"* (OMFS 9).

The end-point of management for all specialties was the pain clinic. This is a generic clinic run by anaesthetists who have an interest in intractable pain and may be attended by people with neuropathic, psychosomatic and other types of pain. It may not therefore be the most suitable end-point for TMD patients.

When asked about the place for a multidisciplinary clinic in the management of TMD, the consensus was that this would be a good idea and its constitution

should be a restorative dentist, a psychiatrist, a imaging specialist, a facial pain specialist and, in some cases, the ability to call on a surgeon if needed. *"I have no doubt that it would be an improvement [in the management of TMD] if patients were to be assessed by a multi-disciplinary team"* (OMFS 6).

The multidisciplinary clinic as an entry point to secondary care, rather than discipline specific entry points, might reduce inter and intra specialty referrals which have led some patients to feel that there is a lack of ownership. This, the patients report, leads them to feel distrusted and labeled as difficult (Section 5.3.5). The multidisciplinary clinic might also help reduce the specialty-limited management that is prevalent within the data and encourage a more comprehensive treatment of the patient.

The question remains: even if a multidisciplinary clinic existed would its practice be based on anything more than experience? All of the clinicians involved in the study readily admitted that their practice is not evidence based due to the poor quality of the evidence.

> *"...in the absence of really good quality evidence, a lot of it's on experience" (RD 2)*

> *"I think indifferent's a good word [for the evidence base]. I've read a few articles in the BDJ that I have tried to piece together.*

I don't really feel that there's a great deal of information readily available on the management" (EGDP 14)

The professionals expressed their determination to try and be evidence based but expressed their difficulties with achieving that.

"I think the evidence is pretty poor…The way Cochrane [collaboration][11] views dentistry it's wheedled down from sort of 2,000 on occasions to three, you know. And you've got to go on something" (RD 8)

The unvalidated and irreproducible nature of the evidence available makes it little use for routine clinical practice. The variability of the evidence is largely due to the lack of a reproducible outcome measure (Al-Ani et al., 2004; Koh and Robinson, 2003). This variability has left the literature in such a state that one of the respondents remarked that he could find support within it for most procedures he might choose to perform!

"Well if I look up a procedure I can pretty much always readily find papers that support it… Eminectomy sometimes works and sometimes doesn't...The reason I like eminectomy is because it's quick and simple and it stays outside the joint… you can do it safely with no more morbidity. You really want to stay outside

[11] An academic organisation that seeks to improve the evidence base in medicine and dentistry by a program of systematic reviews.

the joint because of some of the bad things I've seen" (OMFS 18)

It is probably this lack of evidence and therefore considered practice that impact on primary care. If the scenario is so bleak at postgraduate level how do we relay the information to our undergraduates whom we have taught to be evidence-based practitioners? An uncertainty is bound to come across in undergraduate teaching and at such an early stage in undergraduate educational development individuals may begin to feel this is an area they don't comprehend and can't conceptualise, thereby adding to the fears of misdiagnosis.

The lack of a readily applicable outcome measure contributes to the poor quality of the evidence base for TMD (Al-Ani et al., 2004; Koh and Robinson, 2003) but also, unsurprisingly, has a large bearing on the professionals' assessment of success. Due to the lack of a recognised measure most of the professionals used a subjective questioning of the patient to see if they were tolerating or coping with any remaining symptoms. *"As long as they're comfortable, that's all I want really…. I'm not after a silky smooth joint or anything"* (NGDP 14).

Unfortunately as has been seen in earlier quotes (Section 5.2.2) this can lead to the possibility of explicit or implicit coercion of the patient to admit a decrease in pain and then discharge them with no further thought to their

other potential complaints. *"[Success is] a person who no longer needs to come and see me"* (OMFS 12). *"Realizing that it's perhaps never going to be cured"* (RD 8). The move towards coercion could be accelerated by a negative opinion of the patient involved and the professionals' subjective method of discerning success, which could be used to reinforce that the individual is clinically "better".

There are sporadic occurrences through the data set of practitioners examining some aspect of TMD patients' quality of life. *"Pain free and able to achieve jaw opening that they're comfortable with....But I'd be comfortable with one that didn't if they were able to fulfill their activities in normal living"* (OMFS 18). Judging by the levels of discomfort and distress the patients' report in studies B and C, there is a need for a outcome measure that is patient based and validated. This will serve three functions: it will help indicate to the clinician the psychosocial effects of the condition on the individual concerned; it will inform practitioners of the efficacy of their management and if inefficacious it may help explain why; it will allow reproducible randomized controlled trials to occur to identify the most efficacious treatments for TMD thereby giving practitioners confidence in their clinical practice in TMD.

5.2.4 Summary of professionals' data

The professionals' data set exposes several problems reported explicitly or implicitly about how TMD is managed. There is a time economy issue both in primary and secondary care, albeit reportedly more acute in primary. There is a lack of understanding of the level of patient's distress and pain and therefore a limited awareness of the patient's decreased quality of life. Primary care practitioners feel they lack knowledge of the condition and this precipitates a fear of misdiagnosis.

There is a clear need for TMD diagnostic training to be available for general dental practitioners to help with this problem alongside a brief diagnostic index that is easily applied within the time constraints they are under. Such a diagnostic index would have to: be short to be clinically applicable; have high sensitivity and specificity; have demonstrable predictive validity. The most obvious candidate at present would be a shortened version of the Research Diagnostic Criteria (Dworkin and LeResche, 1992).

Underpinning the lack of understanding and knowledge is the scarcity of good quality evidence to help: a) understand the condition and b) manage it effectively. The evidence base can only be improved with the introduction of a standardised patient based outcome measure that captures the psychosocial effects of the illness and conveys these to the clinician. Without

a standardised outcome measure, the literature will continue to provide conflicting and confusing measures for the profession. This is due to the preference of some authors for inappropriate outcome measures of convenience that do not properly assess the success of a treatment modality.

It is clearly important to try and appreciate the patients' perspective of TMD, as this is a starting point to understanding the processes involved in the mediation between health and illness. This will allow a more thorough understanding of the issues involved in quality of life changes and help with the construction of a patient based outcome measure for TMD.

5.3 "It can be quite reassuring to understand a little bit more about it" - Patients' experiences of TMD (Studies B & C)

Objective - To investigate the psychosocial consequences of TMD for the sufferer

5.3.1 Introduction

This section will discuss the patients' experiences of TMD including their anxieties, their journey through care and the illness' impact on everyday living. During the analysis of the patients' data (Studies B and C) four major themes emerged:

- Genesis of, and reaction, to TMD
- Seeking help
- Negative impacts on everyday living
- Secondary care and coping.

During analysis of these themes, it became apparent, alongside previous analysis of Study B data, that there was a journey that individuals with TMD undertook. This journey involved all of the four major themes and a map of the journey emerged from the data. The emergence of the map of this journey through care is discussed in the next section (Section 5.4) but the data will be discussed in this section to help explain the map's evolution. The following discussion will be illustrated by representative quotes from the data[12].

[12] The letter and number in parenthesis after each quotation give the individual's study i.e. study B or C, and identifier for that study.

5.3.2 Genesis of and reaction to TMD

All patients could detail a starting point for their complaint (genesis) and their reaction to it. Despite all of the patients being able to identify the genesis of their TMD, not all could necessarily attribute a cause to the problem initially. All at the outset experienced pain, mechanical dysfunction or both, in relation to their Temporomandibular joint or muscles of mastication or both. The common features of this pain were that it was of a severe unremitting nature which patients found difficult to communicate often due to its unusual site or radiation.

"Sort of like a migraine type and I've never suffered from migraines before. And the only reason I say that is because when I was sort of speaking to people they were saying oh it could be a migraine. Is it like this, you know, do you … and it was just like … it was quite frightening actually how painful it was. It was very, very sharp and sort of hurting my eye as well. Like almost behind the eye but always on the right hand side…It felt like it was literally the back of my eye." (Pt 6C)

"Eventually it got to a point where I was coming home from work at night time and the inside of my jaw, the right hand side of my

jaw was so weak and my teeth felt so out of place I was starting to feel disfigured, you know, it felt like I was just … it was just ridiculous. And they were just gradually getting worse and worse" (Pt 1C)

The common mechanical dysfunction reported was a reduction in mouth opening that concerned the patient and they felt was visible to others.

> *"Well it's basically a lot of pain and a lack of opening. I've got quite a big mouth and it was all of a sudden it was very painful and restricted in movement." (Pt 5C)*

> *"I was at Wimbledon and my jaw locked and it was embarrassing because the people I was sat next to were looking at me strange because I was trying to unlock it." (Pt 2C)*

Initial experiences or symptoms of chronic illnesses have previously been suggested to occur in a non-serious and serious phase (Stewart and Sullivan, 1982). The non-serious phase was characterised as having an insidious onset where the symptoms could be reconstructed as being due to personal circumstance or another non-pathological cause. The serious phase occurred once the symptoms were experienced with an increasing magnitude or frequency therefore forcing the previous conceptualisation to be rejected.

Within our data these two phases would seem to be true to a certain extent for TMD.

Those patients who had predominately painful symptoms alluded to an insidious onset where they knew something wasn't quite right, recurrent headache etc, but often could not conceptualise a reason for it. This non-serious phase didn't give them enough cause for complaint to seek help immediately in order to legitimise their symptoms, but it still concerned them. Subsequent to this they then, due to lack of intervention or modification of behaviour, experienced an acute exacerbation of their pain and felt legitimised in seeking care, looking to enter the sick role (Parsons, 1951). This acute exacerbation was their serious phase and as (severe) pain is an evolutionary warning signal of potential or actual tissue damage (IASP, 2007) it often caused great concern in our sample, who may have been unaware that pain does not always equate to damage.

Those experiencing mechanical dysfunction appeared not to have a non-serious phase. They experienced an immediate serious phase when their jaw movement became limited. This physical manifestation of their internal symptoms legitimised their complaint to their relatives and they were often advised by their relatives to seek professional care.

The immediate reaction to experiencing a serious phase, in either pain or mechanical dysfunction, was that the patient rationalised a cause for their

complaint or they did not. It was possible for both rationalising and non-rationalising patients to experience psychological distress in relation to the source of their complaint, although this was more common in the latter group. Rationalisation occurred in a manner akin to narrative reconstruction (Williams, 1984) and was more frequent in individuals experiencing mechanical dysfunction; this has symptoms that they easily linked to their jaw such as “clicking” or “locking”. Generally, the individuals who rationalised constructed models of aetiology based on their personal circumstance, experiences and symptoms that were not necessarily true to medical models. Some, however, did have insight to the possible pathogenesis of their problem, which appeared to positively affect their reported treatment outcome.

> *"But it’s when I go to, like, bite it seems like a lockjawy type feeling." (Pt 13C)*

> *“Initially I thought maybe it was a dislocated jaw. I mean I’d dislocated my shoulder before and I just … and it kind of felt a bit similar. So I just thought oh it’s come out, it’s gone back in, maybe that’s what it is” (Pt 5C)*

The individuals without symptoms of mechanical dysfunction in the sample who rationalised tended to rationalise their problem as a consequence of their ear or their teeth, due to what would appear to them to be pathognomonic symptoms.

"I thought well why am I getting pain and why is it going up the side of my face. I mean I I've heard of neuralgia and all those kind of things, you know. But it was in the wrong place for that. … Again it was my ears, I thought well my ears are alright. I even … from time to time I've had…people look at my ears to see if they're actually alright just in case it was my ear" (Pt 15C)

"I actually went to the doctor first because it felt as if I had terrible earache. And every time I went he said he could never see anything wrong. No infection so he couldn't give us anything" (Pt 7C)

This reconstruction of experiences to explain and make sense of a life situation has also been found in individuals suffering from chronic widespread pain (Richardson et al., 2006). In Richardson et al's study individuals were found to use two explanatory frameworks, predisposing factors and triggering incidents, to explain their situation. It was this that helped them adapt to the initial biographical disruption they experienced. Within our data these two features were also used alongside, if present, symptoms that could be linked to the jaw or its musculature. The difference in our data is that due to the variability, fluctuancy and non-pathogonomic nature of TMD symptoms, some individuals were unable to reconstruct (rationalise) their complaint as being related to the Temporomandibular joint or muscles of mastication and they

experienced continued psychological distress until they received a correct diagnosis. The lady below illustrates the distress caused by ongoing severe headaches that she could not equate to a cause.

> *"I was getting a lot of headaches but very, very frequent headaches and I was quite concerned because, you know, you don't know what it is and they were quite sort of intense headaches." (Pt 6C)*

The diagnosis they sought should probably have occurred when they initially sought help within primary care but, as the next section will illustrate, this was rarely the case.

5.3.3 Seeking help

Individuals, as would be expected due to NHS structure, sought help from the primary care sector initially. Some contacted their general medical practitioner and some contacted their general dental practitioner. They arrived at the point of contact having either having self-explained the cause of their complaint (rationalised) or having no explanation in mind for their complaint (non-rationalised). In either case, individuals could exhibit psychological distress in relation to their complaint.

> *"[What do you think made you go for treatment essentially?]*
>
> *Well the pain plus the worry of wondering what was wrong with me. That really got me down" (Pt 5B)*

> *"I was worried about it because I was getting shooting pain right up there, right up the side" (Pt 4C)*

The individuals who exhibited distress reported four classical antecedents to psychological distress (Ridner, 2004):

1) A stressor – this came in the form of symptoms and uncertainty
2) Perception of the stressor as a threat – anxiety over source of complaint and its serious or sinister nature

3) Loss of control – patients were unable to control their symptoms due to lack of information, diagnosis and management
4) Ineffective coping – patients were unable to adapt to the illness due to lack of information on management.

Concern over the source of the pain individuals were experiencing was recurrent through all reports of psychological distress in the data. This concern could be caused by: lack of explanation by the practitioner; anxiety over the nature of their complaint; or lack of, or uncertainty in, diagnosis (in primary care). Even those who had reconstructed their symptoms in line with experiences to explain their complaint were not immune to this distress, as often they didn't receive confirmation of their reconstruction or information on a viable alternative from primary care practitioners.

For the cohort as a whole, this lack of information in primary care meant there was little legitimisation or explanation of the complaint in primary care. This had the potential to worsen any pre-existing psychological distress as the following quote illustrates, *"I think they [the hospital] were going to tell me it was something really serious and I'd have to have an operation or something"* (Pt 2C). This lady had been given very little explanation of what needed to be done for her complaint by her dentist and was told she was being sent to the local hospital to have her problem examined. This immediately increased her psychological distress because she felt, *"the word like hospital is a bit worrying"* (Pt 2C) and she became anxious she might need an operation.

The nature of the complaint also gave patients cause for distress. Due to the magnitude of the pain and its unremitting nature, patients often sought help with a conceptualisation of a sinister or serious cause of their complaint.

"It preyed on my mind…because I did have a big pain, you know. It's funny really when I think of it now [in the interview], the girl I worked with she's got a brain tumour which doesn't grow so nothing's being done about it, she's had it about five years now. She had headaches for a long time, had tests and they found out it was a tumour. You know, it sounds really hard, but you think [patient tails off]" (Pt 9C)

The most common conceptualisation was the possibility of cancer. *"I thought I might have cancer or something awful like that...Because it didn't, as I said, seem to go away"* (Pt 3C). This fear is probably due to the individual's initial representations of the cause of their illness. In chronic illness these are often based around their generalised pool of illness information and their social communications with other people (Goodman et al., 2005). Goodman et al make the point that because Systemic Lupus Erythematous (SLE) is an uncommon illness people have little knowledge about it and few would consider it as a possible cause; two facts that are inherently true in our sample for TMD; *"I mean I know I'm a nurse and I'm in the medical profession, but dentistry, I just didn't have any idea about…how painful it*

[TMD] can be…Or a simple thing that's causing it [TMD]" (Pt 15C). This apprehension was only worsened if there was a lack of, or uncertainty in, the diagnosis.

Any uncertainty in diagnosis in primary care served to heighten the concern and therefore the psychological distress of the patient, possibly shaking their faith in the consulting practitioner. The following individual had a tooth extracted because of her pain, when the pain did not cease she had an extensive examination from her dentist. The dentist, as she recounts, felt there was something wrong but couldn't give a definite diagnosis and referred her onwards to the dental hospital. Later in the interview she tells of her psychological distress due to this uncertainty.

"He [the dentist] did x-rays and different things and he couldn't find anything in, you know, the gums or anything like that. And he decided to refer me … he didn't sort of like mention what he thought it was, but he decided to refer me to the Dental Hospital because he thought there was obviously something going on [but] that wasn't actual toothache as such."

"I just was a bit fearful really because I didn't know what it was… people go to the Dental Hospital it's because they've got major problems" (Pt 15C)

The aetiological role of a lack or uncertainty of diagnosis in causing psychological distress has been reported within the chronic illness literature previously (Borkan et al., 1995; Reid et al., 1991; Scambler and Hopkins, 1986; Shaul, 1995; Taylor, 2005). The uncertainty/lack of diagnosis increased our respondents' anxiety over the potentially serious or sinister nature of their complaint. As they were often enduring ongoing pain, this increase in anxiety and stress will tend to lead to further suffering which has been shown to lead individuals to experience breakdown in their personal narrative (Chapman and Gavrin, 1999). In chronic pain this further suffering caused by anxiety can be attributed, in part, to a resultant decrease in pain tolerance/threshold and magnification of symptoms (Cornwall and Donderi, 1988; Katon, 1996) in addition to the difficulties in social circumstance our sample reported.

In TMD further suffering will be linked to: further inappropriate non-masticatory (parafunctional) jaw activity, further social disability and psychological distress, all of which will increase symptom experience and worsen anxiety over the complaint. TMD patients have been shown to allow their beliefs about pain to significantly interfere with their social functioning (Turner et al., 2001) and some of this may be due to pain related anxiety and fear. Turner et al's study also showed that interference in masticatory and non-masticatory jaw activities were significantly linked to beliefs about pain. There was a stronger association between these beliefs and levels of disability than between pain intensity and disability. This correlates with our findings and may suggest that a lot of the disability reported in our sample may be due to

inadequate psychosocial management of the individual due to poorly structured consultations and a lack of diagnosis.

Reinforcement of the individual's psychological distress occurred with inappropriate treatments they were subjected to. These treatments often failed and then served as source of concern. The story below explains how one individual had multiple treatments at the dentist all of which failed to stop the pain and served to reinforce her distress despite her dentist's attempts to reassure her.

> *"My dentist and myself, thought maybe if we took the back tooth out...maybe that would [make the pain better], but it wasn't. Once that back tooth was [taken] out it [the pain] seemed to be worse. [After all the treatments] I was starting to worry about it, I was imagining everything. I said [to the dentist] "there's something you're not telling me about this" and he [the dentist] said "if I had any[thing serious], you know, if there was anything you'd be away straight away", you know, he says "don't be stupid". But I mean I was getting where I was really, really down about this [the pain]. I had said I be coming to your [the dentist's] Christmas party because I'd been coming so often"*
>
> *(Pt 3B)*

The uncertainty in/over diagnosis also caused some individuals to perceive an implicit diagnosis of stress or psychosomatism. This left them feeling discredited and this is analogous to the process of "felt discreditation" in Charmaz's discussion of the "loss of self" (Charmaz, 1983). The reason behind the felt discreditation is probably due to the "felt stigma" of an individual who can't cope with stress or is a malingerer (Borkan et al., 1995; Goffman, 1963; Scambler and Hopkins, 1986). This could then impact on their relationships and day-to-day functioning even more than the physical symptoms were previously. Again this implicit perceived diagnosis will only serve to heighten the level of symptoms experienced especially if they then feel they "become a burden" to others without a legitimate reason (illness) for this.

> *"And I got to the point where because I'd complained about it so much I just stopped complaining because you feel that you've had everything done for you and no-one seems to know what's wrong. So you think oh maybe it's just me, you know, psychosomatic" (Pt 3C)*

This felt stigma and need for a medical diagnosis as "proof of suffering" has been discussed in relation to chronic back pain sufferers (Glenton, 2003). In that study there was a rejection of the psychological as an explanation of cause, due to the stigma of mental illness and it may be this that our patients feel weakens their claim to restrict obligations due to illness. There was another parallel to TMD in Glenton et al's study in that their participants

described “up and down days” and a lack of “physical signs”, both of which occur with TMD, and in their study they suggested this too weakened objectification and legitimisation of their illness. Clearly a lack of physical signs, for example locking, are not a problem for those with mechanical dysfunction in TMD, but can pose problems for some individuals suffering from myofascial pain, who might find it difficult to get professional recognition of their problem and therefore legitimisation.

This uncertainty and potential discreditation in primary care seems to lead patients to struggle to restore social functioning without knowledge of their true diagnosis similar to that reported in other chronic illness studies (Gullacksen and Lidbeck, 2004; Shaul, 1995). It generally resulted in ongoing biographical disruption until a satisfactory diagnosis was given, similar to other studies (Glenton, 2003; Lillrank, 2003). Diagnosis, in our sample, was only given with clarity in secondary care and given that the Governmental waiting list target for consultation in secondary care is 13 weeks (3 months) (DoH, 2000) the disruption could continue and worsen the complaint for some time. Add to this that modern day culture encourages iterative reflection on identity and this could mean biographical disruption worsens over the wait to be seen in secondary care due to constant reflection on the cause of the complaint (Williams, 2000). Perversely, this potentially suggests that in initially seeking help from primary care the individual’s suffering has increased in the long-term.

Individuals within the sample exhibited what clinicians would term "maladaptive behaviours". In reality they were trying to find an answer (diagnosis) for their problem to relieve their anxiety and may be exhibiting iterative reflection as this individual illustrates:

> *"I used to test it [her jaw and muscles] and also prod away and examine it all the time and examine my mouth. I just think I had a bit of an obsession with it to be honest. "*
>
> "*I must admit, as well, I did worry about cancer in my mouth because I had like a lump. But I've since been assured that that's muscle and the reason that it protrudes is because obviously I've like worked that muscle so much. But, I mean, I used to keep feeling in my mouth and thinking oh I've got mouth cancer and I've … I am a smoker." (Pt 6C)*

Primary care was the starting point for a large amount of the psychological distress experienced by patients. Patients reported varying experiences in primary care, most of which related to psychological distress. The driving factor behind patients seeking advice in primary care was often their pain; this is in line with the literature (Dworkin et al., 1990) and the professional's perspective (Study A, Section 5.2.2) but they also wanted to discuss its psychosocial effects. Their expectation from the consultation, however, was for information on the source of the complaint and its effects rather than

necessarily primarily a decrease in the pain, *"My biggest concern was to confirm that I wasn't going to get arthritis because of the click"* (Pt 16C). They repeatedly received little information on the benign, self-limiting nature of their complaint in primary care.

This lack of information has been found to be common with patients for whom medicine cannot explain their symptoms (Salmon et al., 2005). The patients seek emotional reassurance and information but the primary care clinicians may seek to limit their emotional engagement with the patient due to medicine's inability to control the symptoms. Compounding this problem is the fact that primary care clinicians have been shown to be poor at normalising the symptoms patients report in these circumstances in a manner that reassures them (Dowrick et al., 2004).

Even those individuals who had felt they received some kind of idea of what was wrong with them in primary care felt they were given little information about the condition and seemingly had been given vague details over the potential diagnosis. This is the "functional uncertainty" that Scambler and Hopkins (Scambler and Hopkins, 1986) refer to as being a clinical tool utilised by health professionals in minimising the impact of a diagnosis. This functional uncertainty could be being utilised by the professionals for one of two reasons. The first is that in the professional data (Section 5.2.3) primary care practitioners have reported their concern over misdiagnosis; functional uncertainty can be used to minimise the impact of this. The second, again

explained in the professional data (Section 5.2.2), is that the professionals are aware of the reputation of TMD within dentistry, the supposed needy and emotional temperament and the sometimes heart sink nature of their management. They may, therefore, assume that the patients are also aware of the sometimes-psychosomatic insinuation of TMD and may not want to impose this stigma and have to explain the psychological aspects of the condition to the patient.

> *"And my dentist, he referred us here. Because he seemed to have an idea of what it could be. Because I always felt as if it was my back tooth on the bottom. I mean even like now it's like tender and sore. And yet he said it's okay, you know…Well he [GDP] x-rayed my tooth to see if it was something, you know, a problem there. And he said whilst he couldn't see anything really wrong, and he had an idea, he'd said, you know, the facial pain and that what he thought it was. And he said he would refer us up to the dental [hospital] to have it checked out…He said the kind of facial pain I had he said I think I'll refer you to the experts" (Pt 7C)*

Often individuals were referred on from their initial contact in primary care to secondary care without a clear diagnosis. Referrals between general medical practitioners and general dental practitioners were also reported, sometimes with a differing and confusing diagnosis given by each. Within primary care

several outcomes of consultation were commonly reported: misdiagnoses, no diagnosis and referral to secondary care (sometimes to inappropriate specialities), or delays in diagnosis and management due to the practitioner's reluctance to diagnose and tendency to refer. These outcomes of the initial consultation served to perpetuate the biographical disruption the sample reported. Any form of appropriate reversible management for their complaint was rare, although several individuals had undergone inappropriate, sometimes irreversible, medical or dental interventions.

Research conducted with chronic illness patients and their health care professionals (May et al., 2004) has shown the level of empathy shown by the professional to be related to the options for "disposal" of the patient, that is, where they can be referred onto. It has been demonstrated in our professional data that the tendency for referral in primary care is related both to the fear of misdiagnosis and to the "disposal" of time-consuming patients (Section 5.2.2). Alongside this, TMD patients challenge the "epistemological authority" of healthcare and this too makes referral more likely (May et al., 2004). It is, however, apparent that this process of referral without clear diagnosis is adversely affecting the patient's condition. They can experience loss of self due to ongoing symptomatology, and they may perceive they are burdensome to their relatives without the legitimisation of a diagnosis or physical manifestations of an illness. They may therefore perceive the felt stigma of a malingerer or one with mental illness.

They [her general medical practitioner] thought it was depression because I've had miscarriages … I'd had a miscarriage. Plus my mother-in-law, I was looking after her with her depression. But I said that apart from the headaches I was quite happy, I felt fine. So I had different tablets, nasal sprays. I had Amitriptyline, which is an anti-depressant…They [the general medical practitioner's treatments] weren't affecting, you know, there was no change. So then I was referred to the RVI. I had a few different little tests there and I had a scan in case it was … to try and find [tails off]" (Pt 9C)

The varying reasons behind the lack/uncertainty of diagnosis: functional uncertainty, regret bias, challenge of epistemological authority, unwillingness to emotionally engage, inappropriate consultation techniques, lack of knowledge, all result in ongoing biographical disruption until the patient obtains a diagnosis. They continue to "search for meaning", aiming to define the illness they are suffering from and understand its long-term implications to allow adjustment to its social implications on their everyday lives. They do this to give meaning to their illness; explaining the symptoms they are experiencing thereby beginning the process of "mastery", gaining symptomatic control. All this allows cognitive adaptation to the illness (Taylor, 1983). The prolonged nature of their search in our data tends to mean that they do not adapt as quickly and continue to experience negative impacts in

their day-to-day functioning whilst they struggle to restore meaning and reconstruct a new positive self, independent of their illness.

5.3.4 **Negative impacts on everyday living**

Unsurprisingly the psychological distress, the symptoms caused and the journey patients undertook through care, had impacts on their day-to-day functioning. The impacts can be likened to Charmaz's loss of self (Charmaz, 1983) and they result in varying degrees of social impairment. The impacts occurred at differing points during the patient's journey through care but the precipitating factor appeared to be continuing pain, especially if it remained undiagnosed in primary or secondary care.

The negative impacts occurred in the individual's personal relationships, job performance and social activities.

> *"It [the pain of TMD] stresses you out. You don't really realise when it does. But I was getting upset with my husband, I was coming in from work and … I was really narky and my husband would get it in the neck." (Pt 6C)*

The next quote shows the impact on an individual's working life, the pain disrupting his day-to-day functioning in his work.

"Oh yeah, everything was a lot harder. I mean it still is, even stood here now, it's a lot harder. If I felt 100% like, you know, I mean stood here's not so bad. I mean I do feel better now than when I left the RAF like. But at the time I couldn't ignore it, you know. I did four months in Saudi and I was like getting up on the morning and oh god. That was red hot. You were drinking loads of water out there, you know, and drinking cold cans and stuff. It was just like a nagging, aching … it can make you like bad-tempered" (Pt 18C)

The social consequences of significant others knowing about the pain and the difficulties the sufferer had experienced with getting a diagnosis meant that the sufferer perceived, or felt, a lack of support. They then felt that they were not entitled to the rights of the sick role.

"I think parents and parents-in-law were just kind of fed-up of this woman that was always in pain. Always in a corner, you know, at a party taking painkillers and drinking water rather than having fun. But it was very wearing"
(Pt 8C)

In addition to the precipitating factor of on-going pain there were a number of mediators to the negative impacts: frustration, irritability, suicidal thoughts and depression. These mediators could occur singularly, but usually occurred in

combinations. Frustration was linked to patients' ongoing search for meaning of their symptoms, to help with adaptation, and the effects of the condition on their social activities. They wanted permission to enter the sick role and they felt the need to prove themselves to be in pain due to the often-missing physical signs.

> *"Also when I play the flute I can't play it the way I used to because I can't get the embouchure quite right. I mean I can still play it fine for what I need to do now, but if I was a professional flutist, which I'm not, that would be quite frustrating" (Pt 14C)*

Irritability was reported to be a direct result of ongoing pain, a lack of a diagnosis/management and a lack of sleep in some cases. It seemed that irritability in general had a major role to play in disturbing the patient's close relationships. For some, irritability gave way to anger over the lack of meaning given by the healthcare profession for their problems.

> *"It [TMD] sort of made us, at times when it [the pain of TMD] was really, really bad, a little bit irritable. People seemed to like get on my nerves a bit, you know. I felt as if sometimes I used to take it out on my husband a little bit" (Pt 7C)*

Suicidal thoughts were reported by two individuals and were due to the perception of insurmountable impacts of TMD on their day-to-day living and a lack of help and support from the healthcare profession.

> *"I couldn't sleep because of the pain. And then I would … I literally remember times when my husband was there kind of dripping with a dropper whiskey on the tooth just to … because that seemed to help it, you know. And finally falling asleep and then waking up in terrible pain again and just literally banging my head against the wall with this terrible pain. I mean I'm not in that situation now, the pain's more controlled. But at one stage I was suicidal with it really, absolute terrible pain." (Pt 8C)*

"Depression" was the most common mediator reported. *"Yeah, I'll tell you [with] what I had [I] was really depressed, I can tell you that. I was really sick of it [the constant pain]. I felt right down with it"* (Pt 3B). The depression was attributed to ongoing pain, which was due to lack of management of TMD. It appeared to mediate job performance, personal relationships and social activities. Patients sometimes described its physical expression as a level of introversion, which they attributed to the effort of internally managing the on-going pain. This was often due to their lack of diagnosis which made them feel that they couldn't ask others for help; they then sometimes indulged in "information control" (Scambler and Hopkins, 1986) due to the lack of medical legitimisation for their complaints. *"I kept it [her pain] to myself because I*

didn't want to put it upon others because they [relatives] couldn't do anything for me" (Pt 3C). This often only served to further affect their close relationships.

Depression and its association with chronic pain have been extensively debated in the literature. The debate centres on whether depression is an antecedent or consequence of the pain. Depression is more common in individuals with Myofascial pain (Korszun et al., 1996) but a familial study has shown that it is not antecedent to the pain but is likely to be a consequence of it (Dohrenwend et al., 1999). This supports the diathesis-stress model, which our data would also support; the continuing pain and uncertainty over diagnosis cause delegitimisation of the complaint, which leads to depression, which mediates negative impacts on day-today functioning, which in turn can feed back to worsen the depression. In addition to this, there is physiological evidence that neurotransmitters linked in depression and chronic pain, serotonin and norepinepherine, have major roles to play in TMD (Costello et al., 2002; Kopp, 1998; Okamoto et al., 2005; Rodrigues et al., 2006). It may therefore be there is a physio-sociological axis in TMD, with one influencing the other.

5.3.5 **Secondary care and coping**

It often took a number of weeks for the patients to receive an appointment for secondary care. In the intervening time they continued to theorize about the source of their complaint due to the ongoing psychological and physical

distress they were experiencing. Although those who had rationalised a cause for their complaint did not explicitly mention their anxiety over the cause of their complaint, they did implicitly suggest their concern on attending secondary care. All patients mentioned the relief of receiving a diagnosis and supporting explanation/information almost immediately in secondary care. They implicitly stressed the importance of that diagnosis to them and their recovery.

> *"I didn't have this before now I have it. Why do I have it? I was then told what it was [in secondary care]. It wasn't something I should be overly concerned about. It won't affect … as I've found out, it won't affect my day-to-day life. And so if nothing more it set my mind at rest that I've got this condition, it's not dangerous to your health, chances are very good for having it corrected, so that's fine by me. " (Pt 11C)*

> *"I wasn't necessarily thinking of the cure, more of knowing what was wrong with the jaw. That was, I think, the primary thought in my mind was I wanted to know what this was. And then I think the cure was second" (Pt 5C)*

The information they received, or found themselves, alongside their diagnosis allowed them to reconstruct their representations of the complaint. They began to understand its nature and longevity, and this generated an emotional

response of relief similar to other chronic illness studies (Goodman et al., 2005; Salick and Auerbach, 2006). After receiving the diagnosis and accompanying information they alluded to self-initiating coping strategies, such as social comparison (Lee and Poole, 2005). This was utilised against the original lack of legitimacy of their complaint. They reported the liberation of having a reference point and knowing they weren't *"the only one"* (Pt 13C)

> *"And I think the reassurance was once it was almost like somebody [secondary care] had said to me hang on a minute, this is what we think it is. And as soon as I had sort of been given this name I did look on the Internet and I thought yeah that sounds like what I'm going through. And when I attended here [secondary care] and realised that there was other patients here with the same condition. And speaking to people, I'm surprised at how many people I actually know who actually wear splints. I didn't realise … do you know what I mean" (Pt 6C)*

> *"I mean you had a name for it and you knew you weren't alone with it so it eased your mind totally really knowing that it wasn't anything too serious" (Pt 7C)*

As illustrated by patient 6C above and patient 9C below, social comparison was not the only self-initiated coping strategy undertaken by the cohort once a diagnosis was given. Others searched for information on their diagnosis from

different sources and tried to correlate their symptoms with other narratives or information found (Sarafino, 2002).

> *"Yeah. Information I received, you know, the sheet I received [in secondary care]. I looked at that and also looked on the Internet to see what I can find. And it ties in all these things like my neck and shoulder. Yeah, I think it's really helpful. It takes the stress away really. You know, you're not a one off." (Pt 9C)*

From their reports individuals' whole quest for a diagnosis appeared to be about answering "why", an emotion based coping strategy (Lee and Poole, 2005). The answer to the question would appear to allow them to institute acceptance of the condition and thereby start the process of adjustment to it. It also legitimised their complaint and allowed them to enter the sick role whilst seeking to achieve symptomatic control of their complaint; a process similar to achieving mastery in Taylor's model of cognitive adaptation (Taylor, 1983). The individuals interviewed, explained that their treatment expectations were often very high initially but after diagnosis they reported the ability to set firm realistic targets for improvement, another coping strategy aimed at emotion (Sarafino, 2002).

Individual's expectations of outcome were often different to the clinician's but they still were prepared to achieve concordance and start the process of adaptation aiming for realistic palliation of symptoms.

"You want a magic wand waved over and then it's [the pain] gone [individual is cured]. You come here [the hospital], you go home, then it's [the pain] gone... Then reality kicks in and you think no that's in never never land [a complete cure], that's not the way it works… I've had to adapt, I've had to just cope [with the diminished remaining pain], because if I didn't I would just give in and just give up and just curl myself into a little ball and forget about" (Pt 13C)

This quote illustrates, similar to other findings (Ong and Hooper, 2006) that a lack of concordance initially may not always result in a poor outcome for management as long as careful realistic explanations of management are given alongside emotional reassurance (Salmon et al., 2005). The patients exhibited less demand on clinicians than they are given credit for in the professionals' data, illustrated in the previous chapter (Section 5.2.2). This suggests that the heart sink nature of TMD within dentistry (Section 5.2.2) maybe biasing the clinician's judgement and could also be one of the reasons why the professional may not emotionally engage with the individual.

There were patients within the sample who had cyclic consultations within primary and or secondary care; that is they re-presented to the same or differing clinicians still seeking a diagnosis for their problems. Once gaining a correct diagnosis eventually, these patients had difficulty in gaining

confidence in that diagnosis and were critical over the disciplinary limited view of the clinicians they encountered in their cyclic path. Throughout their cyclic consultations they wanted to have a clear label (diagnosis) and with it the legitimacy, which it confers to their complaint. This need for a label will be further discussed in relation to improvement in TMD a little later in this section.

> *"Everybody likes to have a name for what they're suffering from, I mean, you know, even if it's a terminal illness at least you know what you've got, you know, you can come to terms with it more. But I think what I found difficult is that I've seen so many different people, you know, dental people I've seen, you know, psychologists, I've seen a chiropractor – I forgot to mention that. The acupuncturist. And everybody's really existing in their own little field. And I found there hasn't been a great deal of crossover... And it's not a joint attack, it's been that single-minded. And you're kind of pigeon holed and put in a box and sometimes I think right I would have benefited from if there'd been more sharing of information amongst the specialists and maybe a more all rounded approach...when that single-minded attack hasn't worked then I've been dismissed and passed on to somebody else. And this has been going from pillar to post" (Pt 8C)*

Patients within their experiences of secondary care explicitly and implicitly alluded to the fact that they felt they had improved to the extent that they needed no further secondary care. They felt they could manage the condition themselves and they understood the importance of self-management.

> *"And that I can, you know, control it. Because as it is now, I know I do have bouts, but because I know what it is I'm not sort of … because I think what would happen is you would have the pain … because I've got it a little bit there now. I [used to] just think about it all the time whereas I forget about it [now]. And once you forget about it, it's not really as bad as what you think it was to begin with" (Pt 3C)*

> *"I've got to the point now where I think I've got to do it because I can only help myself now, it's not a case of … I could come here for the next 12 months but unless I continue to help myself it's not going to get any better as well" (Pt 6C)*

There were four factors, which emerged from the data that influenced the patient's reduced need for ongoing secondary care. In those who qualitatively suggested they had no need for ongoing secondary care those were:

1. Confidence – in their own ability to self-manage the condition and in the clinician and their diagnosis
2. Understanding source of complaint

3. Possession of reference point

4. Reduction in pain

Self-management was made possible by the diagnosis and the degree of information given to the patient. Within the data it was apparent that patients gained confidence in their ability to self-manage over time, especially if pain levels decreased for sometime. They generally accepted that they might never be totally pain free.

> *"No, I felt more positive about it, because I realised that … well it put a label on what it was, I knew that it wasn't my ears and it wasn't my wisdom teeth and it was actually the fact that it was a problem with my jaw. And I felt a lot happier because obviously they told me that there might be some type of things that they could do to, you know, make it a bit better." (Pt 10C)*

In the quote above patient 10C explicitly mentions the importance of a label, she has resolved her primary deviancy (Lemert, 1972), which was related to lacking a diagnosis. Now she has a label she can seek societal legitimisation by word of mouth to her close friends or relatives. Depending on her label, however, it is now possible for secondary deviancy to occur and her complaint to act as a stigma (Goffman, 1963). In this lady's case though, her label was TMD and this as a stand-alone diagnosis appears, through our data, not to have any stigma associated with it in the general population. This is compared

to the negative opinions of the professional body treating it (Section 5.2.2). If the general population widely and explicitly knew these opinions, it might make TMD a stigma as well as a diagnosis.

The diagnosis, and therefore the label, undoubtedly had a therapeutic effect, alongside the explanation of the condition and its sequelae as is shown in the quote below.

> *"I think it can be quite reassuring to understand a little bit more about it... So me having information has sort of assisted. It's helped me understand and know that … I think even daft things like eating things…Like chewing gum that was it. I think I was advised against sort of having chewing gum because obviously it will aggravate it. So I did, I thought to myself yeah, you're right, I used to chew a lot of chewing gum and I thought god, yeah, my jaw used to ache. So I don't. I hardly ever have chewing gum now." (Pt 6C)*

Individuals expressed the positive effect of having a reference point. This was usually gained by chance, for example, discussing things with friends and finding they had TMD or by overhearing other individuals on the TMD clinics. The possession of a reference point impacted on their self-management ability, in that they felt they could manage it if others could. This finding may suggest that, for some individuals, patient led therapy groups such as those

within the expert patient program might be useful (DoH, 2001). Their use, however, would have to be tempered by the individual's likelihood to somatise further.

> *"Well you know when you're sitting waiting on Professor [clinician's name] coming round actually to have a look and what have you and there's obviously a lot of people sitting in the chairs doing the same thing. And you can hear what people are saying, you know, when you're in close proximity. And there's an awful lot of people have got the same symptoms as me. And I thought ah well it must obviously be a common thing and people are starting to obviously understand what's causing it now, you know. Which makes you feel a bit better because otherwise, you know, it's not a rare thing that I've got, it's quite common. And I think that's helped, that's half the battle really" (Pt 15C)*

It did not appear necessary for the pain to stop for adaptation and coping to occur. Patients described it as needing to decrease to a level that was "manageable". This "manageability" of their pain and symptoms and confidence in their ability to manage them parallels a process of restoring perceived control and therefore restoring self-efficacy (Keefe et al., 2004). The level of self-efficacy relates to the individual's inner belief that they can

manage the consequences of their illness. It is one of the drivers behind the Government's program of "Expert Patients" (DoH, 2001).

Self-efficacy is known to moderate or mediate the adaptation process to chronic illness, decreasing the amount of disability (Schiaffmo and Revenson, 1992) and the levels of psychological distress reported (Abraido-Lanza, 2004). These findings have been confirmed in studies with TMD patients (Brister et al., 2006). This study also found that lower levels of pain were significantly associated with higher levels of self-efficacy. Low self-efficacy in TMD patients predicts momentary pain and increases its magnitude (Litt et al., 2004).

The evidence of a role of self-efficacy in the process of adapting to chronic illness explains some of the journey through care. Individuals are uncertain over the cause of their complaint, they lack knowledge of how to manage it and they seek help only to find no legitimisation and no advice over restoring control at their primary contact. This has implications for the level of self-efficacy, which will remain low and will mean they experience more pain and as a consequence, greater concern (Brister et al., 2006; Litt et al., 2004). This will mean that they present with an increased need for explanation and emotional reassurance (Salmon et al., 2005) appearing "needy".

Increasing self-efficacy (Lorig and Holman, 2003; Lorig, 2003) is possible by four mechanisms: 1) Skills mastery; 2) Modelling; 3) Reinterpretation of

symptoms; and 4) Social persuasion. Skills mastery involves the formulation of an action plan for that week; the premise being that confidence improves when one does things that work. In the reported journey individuals undertake through care this is not possible until they reach secondary care. Modelling involves learning from others' actions and beliefs; in the journey through care it is obvious our sample are unaware that they are not alone and therefore cannot model until diagnosis. This process mirrors the need our patients expressed for a reference point. Reinterpretation of symptoms is a process by which symptoms are reconstructed positively as an entity that can be addressed; again the data suggests that individuals undertaking a journey through care lack the information, until they reach secondary care, to do this.

Social persuasion is one of the more powerful mechanisms for increasing self-efficacy. Support from the individual's relatives can help encourage the individual into adaptive behaviours; something as simple as changing the family's meal to a less "chewy" one when the individual is undergoing an acute exacerbation of TMD could help greatly. When others perform, or help to encourage, the required behaviours it makes them more likely to be implemented. This, as previously illustrated, is unlikely to be possible until diagnosis, as only those with physical manifestations of their problems are likely to be able to enter the sick role and therefore be legitimised in the eyes of their relatives.

"I think … what would have made it easier for me generally would have been the acknowledgement of the fact that a problem with the jaw can cause such bad headaches that you can't function and therefore you can't work. Because I thought and felt that people were looking at me. You know, you're pulling a leg here, you're … this is … you're over-exaggerating or your off with a headache because of your jaw and that doesn't make any sense. There isn't, and when I've mentioned like TMJ or wearing a splint or whatever, people don't know what it is or don't understand that there could possibly be a link between grinding your teeth or having a clicking jaw that would actually give you a headache. So I suppose awareness… Certainly public awareness or employer awareness.... they [her employer] thought that I'm going completely crackers here everybody thinks I'm a complete looney because she's off with a headache because her jaw's aching. It does sound crazy" (Pt 16C)

One individual, who was within the health profession (Pt 15C, Section 5.3.3), but still did not know of TMD, reiterated the need for society to be more widely aware of the problems that TMD can cause. This would have to be approached carefully so that TMD did not become a stigma due to the negative perceptions of TMD in the dental profession (Section 5.2.2).

The two most important factors for individuals to feel that they no longer required secondary care seemed to be a reduction in their pain and the reinforcement and belief in a diagnosis, as those who qualitatively required ongoing secondary care seemed to lack these.

> *"Well it's some comfort to know there is something wrong. Even better if you can be helped with it, right. But, I mean, I've got Fibromyalgia and chronic fatigue – get no help from that, yet they tell me what it is, I don't know a lot about it, I don't get help with it. I have to tolerate, I have to put up with it. But the fact of the Temporomandibular problem – yeah I know what that is, and the fact that I've got some help with it is a great relief. And I do think this splint is doing some good. And hopefully it continues, even if I've got to wear it forever and a day. I'd wear it" (Pt 16C)*

The underlying implication in the reports of those who appeared qualitatively to require ongoing secondary care was a lack of reported: acceptance of their diagnosis, and self-efficacy. Acceptance in psychological terms refers to the patient's ability to accept that the consequences of their illness are inevitable and that allowing attempts to control them to dominate their lives will simply encourage further biographical disruption (Keefe et al., 2004). The lack of acceptance in our sample was related to the number of consultations individuals had undertaken or lack of concordance with clinical expectation of outcome. Patients either found it difficult to believe their true diagnosis due to

multiple misdiagnoses; in one individual's case (Pt 8C) she had had six consultations all with differing diagnoses before finally receiving the correct diagnosis. Her account of these misdiagnoses illustrates the doubt that can be created in the patients mind:

"Well I still worry about it [the condition and its pain]. I still worry about it now because it's still with me. And even last night I'd be sitting there with the water and the painkillers. It hasn't gone away, and it still originates from these two teeth, and I still think that maybe … because maybe I should have the teeth out. Maybe it's still a dental problem. So no I still … I do, I do worry about it. And I worry about where it's going to go from here, as I get older and the problems become more acute…. At one point I had a [pause] when I saw Mr [clinician's name and location], at one point I had a scan, a brain scan, to see if there was any abnormality. And I also had my, can't remember what they're called now, parotid ducts? [pause] Examined in case that was causing it. I also had an examination of my sinuses. So yes, yes. And I also, because of my [pause] I have a lot of middle ear problems, I was concerned about the fact that my hearing was deteriorating and I was terrified that it was all connected. In fact I'm still not convinced it's not.... So, yes, of course. I mean I still worry about it. As you get older it's a worry about how where it's going to flare up again" (Pt 8C)

Acceptance of the condition could also occasionally be undermined by a lack of concordance between the patient's and the clinician's expectation of treatment. Most patients were able to achieve concordance with the clinician once they had a diagnosis and understood the long-term prognosis for the condition; some however, still expected a cure. These individuals understood their diagnosis but still had high expectations of the ability of modern medicine to cure their problem. They expressed dissatisfaction with the management available for their problem and wanted more from the profession, they perhaps required more explanation of the chronic nature of the illness in order to understand they weren't just being placated. Increasing these patients acceptance of the available management and its likely outcomes is important, as greater acceptance is linked with lower pain intensity, less pain related anxiety, less depression and less physical and psychosocial disability in chronic pain patients (McCracken, 1998).

> *"A successful treatment to me would be my jaw correctly up and down, the feeling that my mouth is big enough to take my tongue and I can speak properly, and my teeth to be re-aligned so that fit right. Just think they don't fit right*
>
> *I think Mr [consultant's name] discharged me [Interviewer - How did you feel about that?] I felt like I didn't have a choice…Because he explained to me that any re-alignment that … or he could refer me to oral surgery or the re-alignment*

doctor, sorry, but he felt that there probably wasn't a lot of chance of … a good success rate" (Pt 1C)

The lack of self-efficacy implicitly reported by those who stated they required ongoing secondary care appeared largely due to a lack of perceived control over the pain. This tended to occur alongside a lack of acceptance of the condition rather than as a separate factor influencing the need for ongoing management. Lack of perceived control over symptoms has been found to be high in TMD patients (Stockstill and Callahan, 1991; Turner et al., 2001). If the level of self-efficacy is low its psychological inverse "helplessness" (Keefe et al., 2004) is likely to be high. This essentially means a fatalistic approach to management of symptoms may be adopted. The diagnostic uncertainty and lack of management generally cause sporadic transient occurrences of helplessness to be reported on the map through care. They are transient, it seems, due to eventual diagnosis and a reduction in the level of pain. Those patients who required ongoing management seem to be still affected by helplessness due to the lack of a acceptable reduction in their pain. The effects of helplessness may be worsened in their case as they have finally received a diagnosis and the profession is seemingly failing to manage it effectively.

Examining the themes that emerged from the data in relation to outcome of management in secondary care against the available literature on chronic illness management, it appeared clear that secondary care management

implicitly seeks to develop active self-managers (Jerant et al., 2005). Active self-managers participate in shared decision making, strive to maintain their social roles and utilise coping strategies well; key abilities in relation to the three major challenges chronic illness sufferers face (Lorig and Holman, 2003). The beneficial effects of self-management programmes for chronic illness have been widely reported (Deakin et al., 2005; Gibson et al., 2003; Lorig et al., 1999, a, b; Trojan, 1989; Winkler et al., 1989). They are aimed at developing skills in problem solving, decision making, resource utilization, taking action and forming professional relationships. Implicitly in the data in the main, these are the skills our patients are reporting (Table 5-2)

Table 5-2 - Examples from the data of the five key skills of self-management

Skill	Example of skill
Problem solving	*"I know now not … that this is possibly what it is and therefore not to try and force it, just to eat soft foods. So you kind of compensate, you don't … you don't open your mouth as much for talking, you find ways around it. So you find that you relax your jaw and that's when, you know, you don't get any pain relief in that, it's just when you're trying to force it or over-use it. You notice the pain" Pt 5C*
Decision making	*"So I'd left thinking oh I'm going to have a click but at least I'm not going to get arthritis. That's a huge relief, great. I felt high as a kite. The fact that I've come back now, three months later, and I don't have a click, is like mega bonuses. And I don't care about wearing the splint, the soft splint for the rest of my life if I need to, if it needs it. I'm not going to make that ridiculous noise and I'm not going to have arthritis" Pt 16C*
Resource utilisation	*Information I received, you know, the sheet I received. I looked at that and also looked on the Internet to see what I can find. And it ties in all these things like my neck and shoulder. Yeah, I think it's really helpful. It takes the stress away really. You know, you're not a one off…It was after I'd been here. I'd found a website where people were talking about their symptoms and what they'd been through. And I thought oh well that's, you know, that's like what I've had. It's nice to know you're not the only one" Pt 9C*
Forming health care partnerships	*"Yeah I think [information helps]… and particularly this morning, actually, talking to Dr [clinician's name]. Yeah and he was lovely. And talking to him I kind of realised that I've got to look at my life balance sort of thing. And the reason why I grind my teeth. [starts to cry]" Pt 14C*
Taking action	*"It [her TMD] can still come back, but I know how to deal with it now " Pt 7B*

At present the initiation of this self-management training is delayed until secondary care with its content appearing variable. This is probably due to a lack of appreciation of the wider evidence base available outside of dentistry and experientially based practice (Section 5.2.3). The data reported in this study points towards the beneficial effects an early and more structured introduction of this type of training might have on TMD patients that are routinely referred to secondary care.

5.3.6 Summary

Individuals suffering from TMD could experience either a non-serious and/or a serious phase to their complaint. The latter phase made them seek help looking for a diagnosis for their complaint. Some individuals, due to symptoms that were pathognomic of their complaint, had rationalised their complaint as being from their jaw but others had not.

The initial point of contact for help was primary care either with their dentist or their doctor. Individuals often attended with some degree of psychological distress over the source of their complaint and they sought a diagnosis and the legitimisation and reassurance it hopefully brings. Unfortunately in primary care a (clear) diagnosis was rarely given and the sufferer became more uncertain over the nature of their complaint. This in some situations led to further discreditation of the individual often due to a lack of physical signs of the complaint.

Primary care often referred onwards, commonly to secondary care, for diagnosis and management of the individual's complaint. During the wait to be seen in secondary care the individual struggled to restore function in daily living against a background of continuing symptoms and uncertainty. This inevitably, for some, led to negative impacts on their day-to-day functioning which served to perpetuate the psychological distress they were already experiencing.

Sufferers often arrived in secondary care with varying degrees of psychological distress and disability. They were still searching for a diagnosis and information on managing their complaint. These two factors had a large bearing on their adaptation to the illness along with a reduction in the level of the pain they were experiencing and a reference point so they knew they "were not the only one". Once this was established they often implicitly reported improved self-efficacy and coping strategies to the point where they felt able to self-manage the illness without ongoing secondary care.

There is a clear journey individuals suffering from TMD undertake in their search for a diagnosis and management. This journey is illustrated in the reports of this chapter and will be depicted in map form in the next chapter. The journey is primarily the result of the fluctuating, intense and sometimes non-pathognomic symptoms of TMD, which sufferers sometimes struggle to reconstruct correctly due to the lack of public awareness of TMD. This struggle leads them, appropriately, to seek help, information and reassurance

from the healthcare profession, but unfortunately their journey is perpetuated by their initial consultation and perhaps their condition worsened by the further uncertainty that this brings.

5.4 TMD sufferers' journey through care - Evolution of a map through care.

Objective - To develop a conceptual map of patients' experiences of, and journey through, care

5.4.1 Introduction

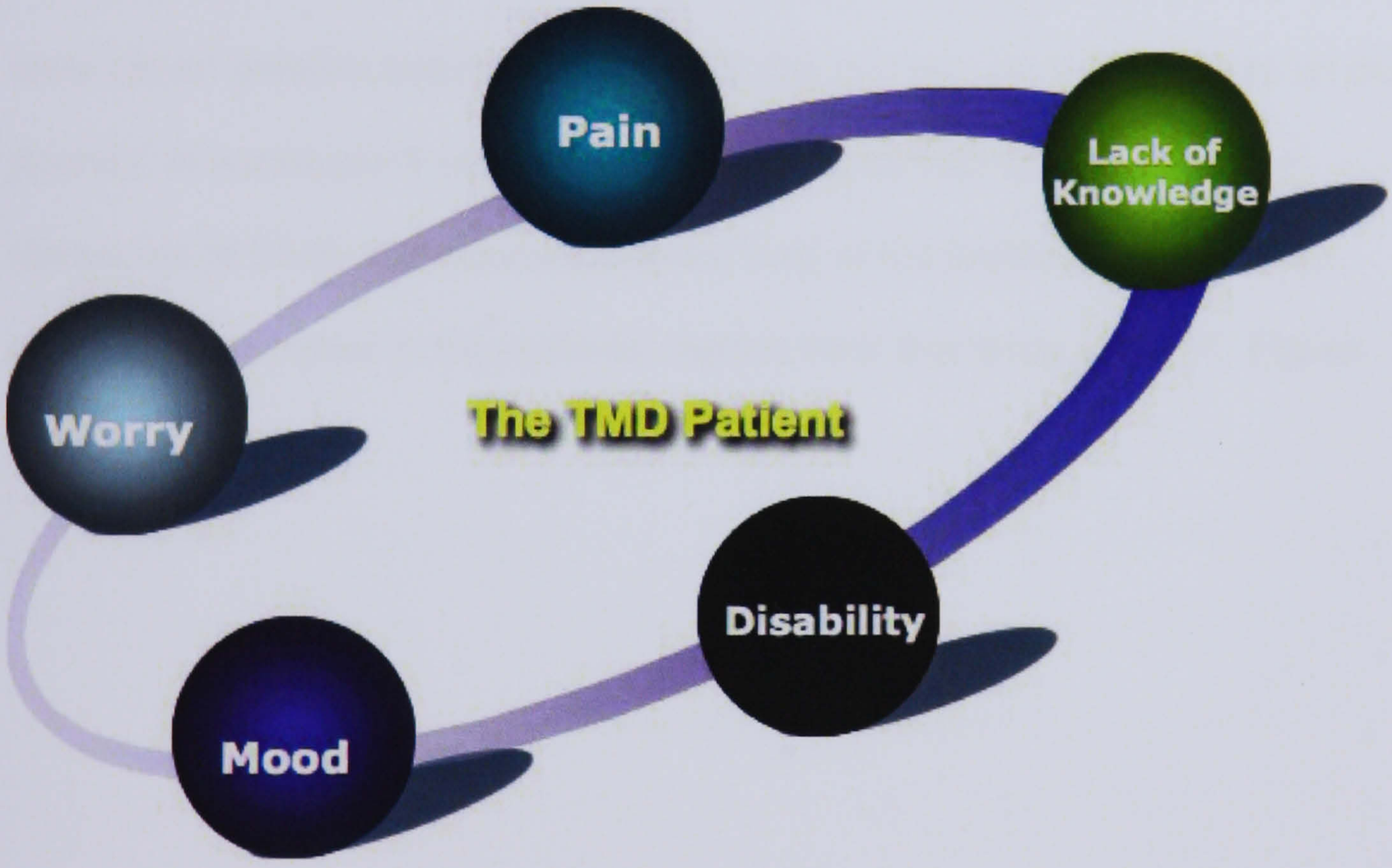
Through the collection and analysis of the patients' data (Studies B&C) experiences were reported recurrently that began to suggest there might be a common journey through care that TMD sufferers travel. Some of the occurrences of this journey were first identified in study B, whose primary aim was to discern the reference period. These occurrences were initially presented as a "vicious circle" from study B's data (Figure 5-2).

Further investigation of the "vicious circle" by reanalysis of all of study B's data by myself (Section 4.3.3), produced a nascent map of the patients' journey through care. However, due to the sample and the original aim of study B, study C was necessary to investigate further the initial map generated. In the last section (Section 5.3) the sufferers' experiences of TMD and their journey through care were discussed. In this chapter the chronological emergence and development of the final map of this journey is explained.

5.4.2 **Emergence of factors in Study B**

Ten in-depth interviews were carried out with patients suffering from a variety of Temporomandibular disorders. All of these individuals had undergone different treatment modalities for varying periods of time (Section 4.3.2). As an incidental finding during analysis to identify a review and reference period, a number of factors that impacted on the patient were discovered. It seemed that these factors encircled a TMD patient and initially inhibited their successful management, a so-called “vicious circle” (Figure 5-2)

Figure 5-2 - The "Vicious circle"

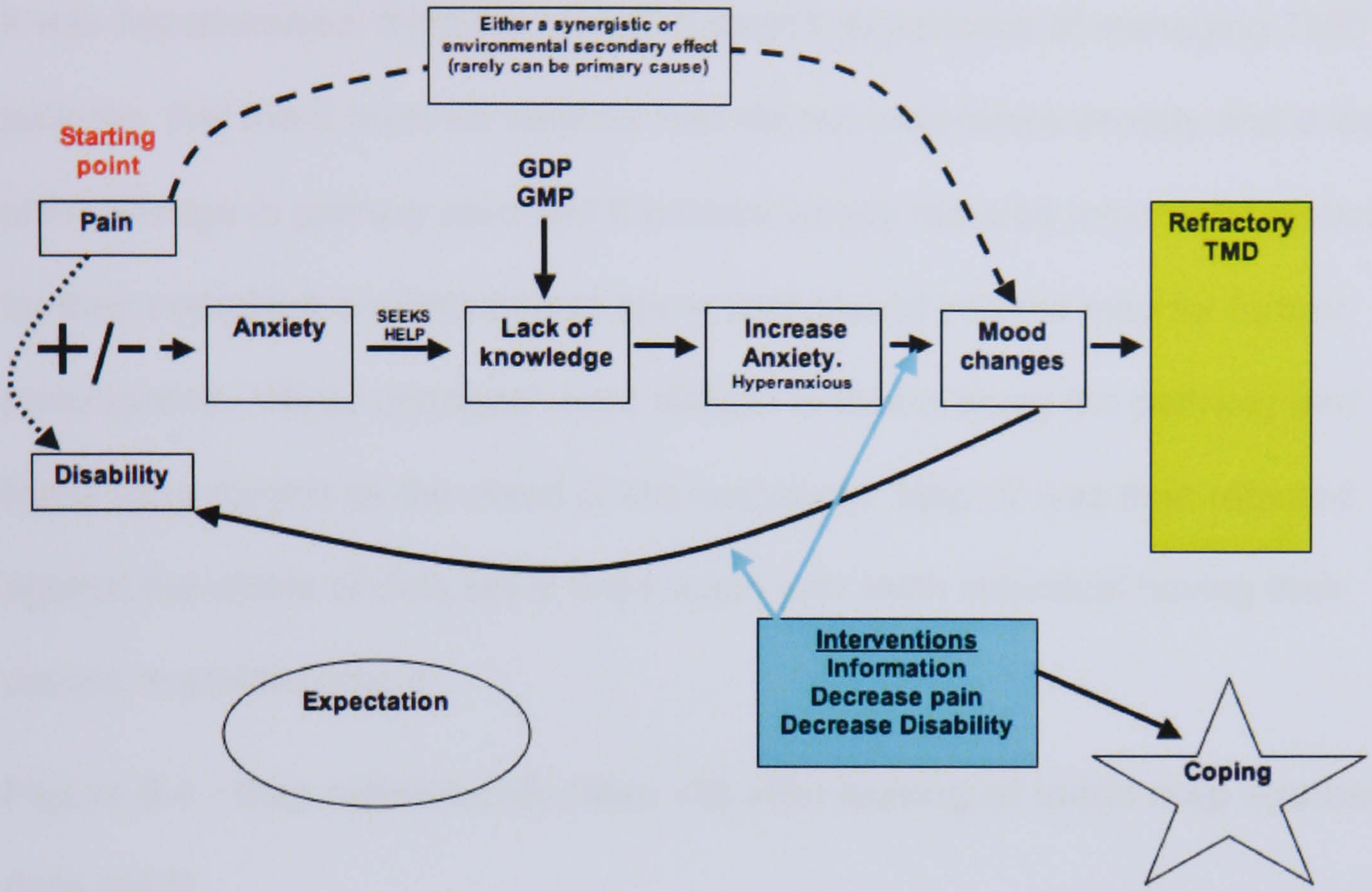


It appeared in this initial analysis that the components of the circle (worry, pain, lack of knowledge, mood and disability) impacted on the patient’s recovery. So for example, if a patient did not understand/know their diagnosis they would reportedly be slower to respond to treatment. If they were aware of

their diagnosis but were still worried over the source of their pain this may cause mood changes but in either case would slow their recovery. Key to reported recovery was the identification of which factors of the circle were present and inhibiting the patient's recuperation.

After recoding and reanalysis of all of the data from Study B it became apparent that not only were the components of the circle substantiated by the professional data (Study A) but they were occurrences on a journey that the patients reported they had embarked upon on their way to care. The components of the circle (worry, pain, lack of knowledge, disability and mood) were either: present before embarking on the journey; caused at points on the journey; or worsened during the journey due to clinical experiences. The reanalysis of Study B produced an initial map of the journey through care, which was grounded in the patients' reports from that study (Map v1, Figure 5-3)

Figure 5-3 - Initial map of the journey through care constructed from reanalysis of factors in data set B (map v1)

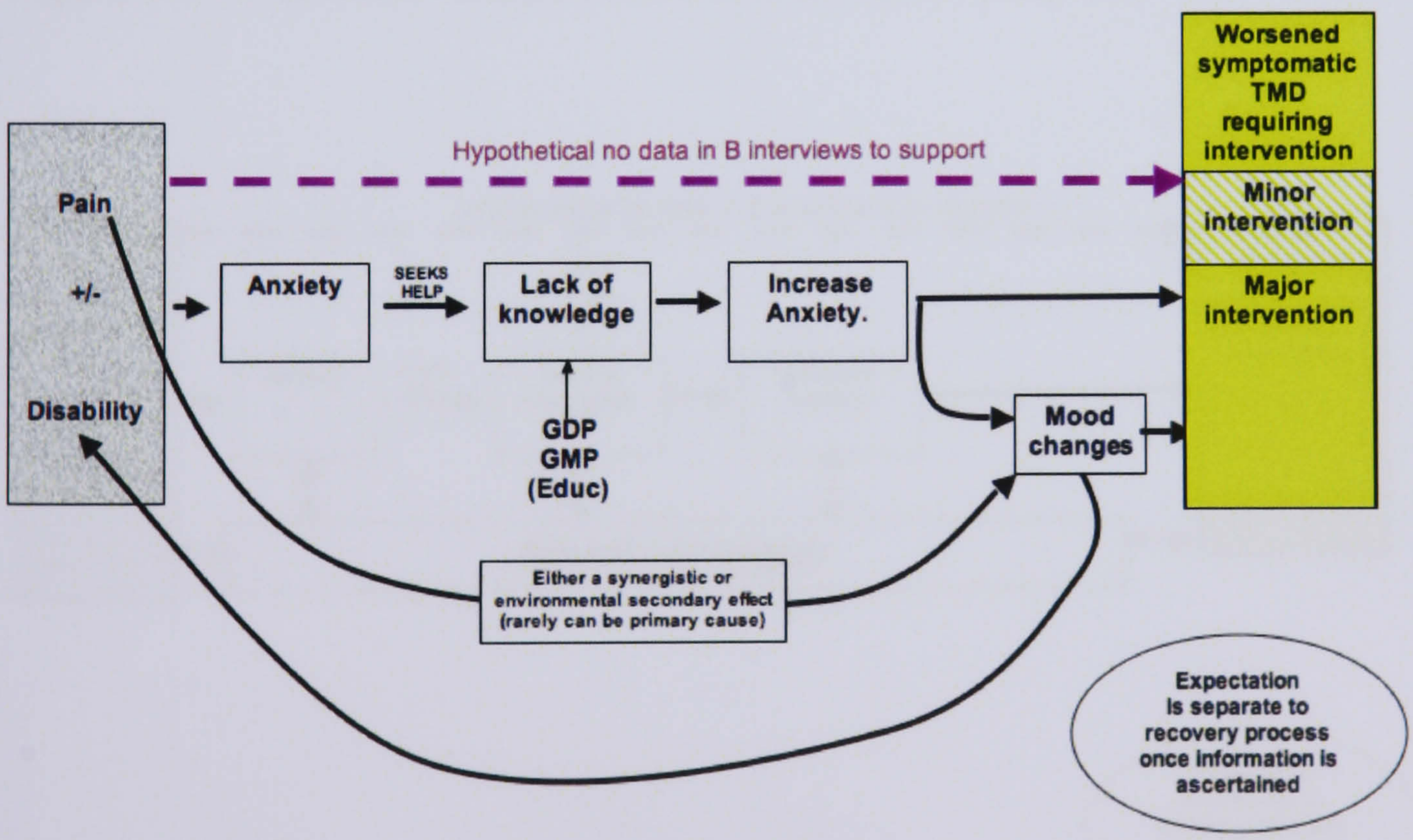


This initial map (map v1) was reapplied to the data gathered in Study B with each individual patient having their path plotted onto it. On reapplication to all of the data in Study B the map appeared to be too complex and was modified to a simplified form (Map v2, Figure 5-4). It was felt there was insufficient data to justify the use of, “coping” and “intervention” in the map and these were removed. “Refractory TMD” was removed, as it could not be proven from the data set that this was the case. A simpler term of “worsened symptomatic TMD” was applied as an end point to the path. This was subdivided into minor and major interventions required. Minor intervention was felt to be an individual who responded to conservative management after one or two visits

and major intervention was any individual who necessitated more visits and an increased level of management.

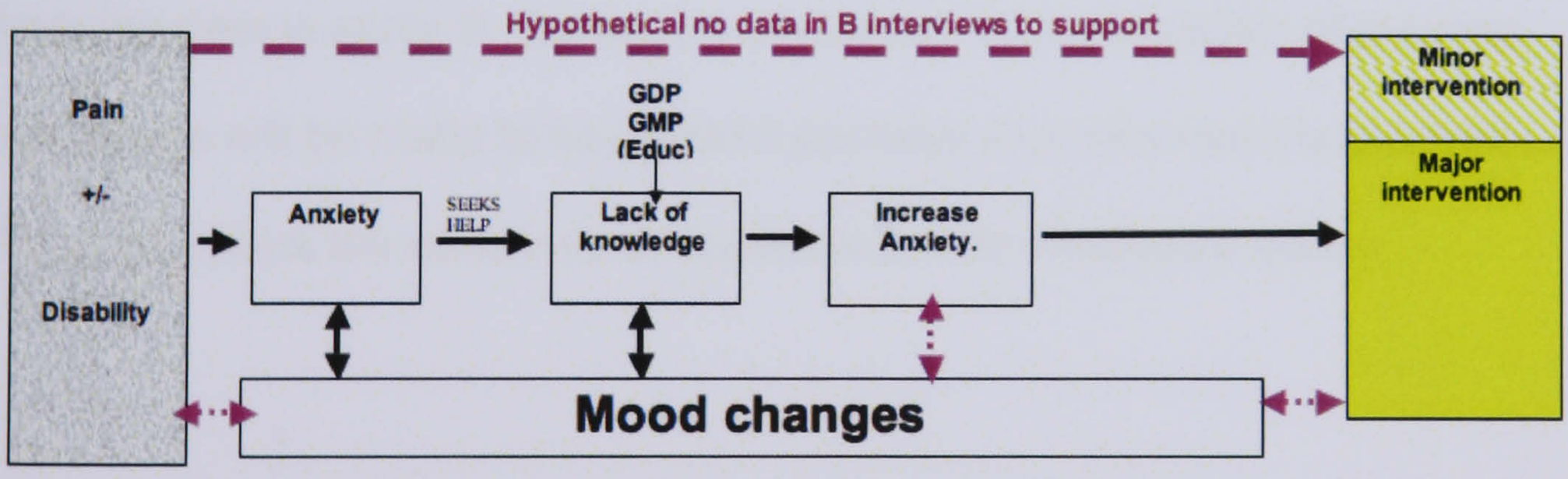
It was hypothesised, from the research team's experience of managing TMD patients, that there must be patients that did not experience anxiety and a lack of knowledge in primary care and therefore simply required minor intervention for their complaint and this dotted arrow was placed into the map for further investigation. "Mood changes" were difficult to locate along the pathway and these were moved as the result of the reanalysis. Map v2 was then retested against the whole of data set B once again with each individual having their course re-plotted onto it.

Figure 5-4 - Map refinements (Map v2) after testing of initial map against data set B



The reapplication of map v2 to data set B showed that there was no data to support the hypothesis of avoiding the whole path thereby necessitating only minor intervention. However, as the a priori clinical knowledge of the research team suggested this might be true, it was left in for further testing. It also became apparent that “mood changes” underpinned a large part of the path and they were moved accordingly. It was hypothesised that these mood changes could also interact in the later parts of the path and these interactions were drawn in (dotted mauve arrows). The new version of the map (Map v3, Figure 5-5) appeared after multiple reapplications against the data from study B appeared to be valid, at least for this data set.

Figure 5-5 - Map after reapplication to data set B. (Map v3)



Expectation is separate to recovery process once information is ascertained

It is important to note, however, that there were two deviant cases; patients 6B and 10B who only followed some of the map but not all of it. They both appeared to have some understanding of the cause of their problem before attending their general dental practitioner. This seemingly prevented them from experiencing initial anxiety about the problem. These cases were noted and it was decided to investigate these during the second data collection, Study C.

5.4.3 Investigation of emergent map of journey through care.

To address the previously discussed problems of study B (Section 4.3.2) and sample appropriately to investigate the emergent map, a second qualitative study was designed (Section 4.3.3). This utilised the data already gathered in studies A and B to inform the topic guide and a purposive sample was taken to identify a cohort of individuals who would address the remaining questions from the data in study B. During the discussion of the evolution of the map references will be made to key patient journeys that informed the process. These journeys are contained in Appendix 3, with illustrative quotes.

5.4.4 Evolution of map using studies C and B.

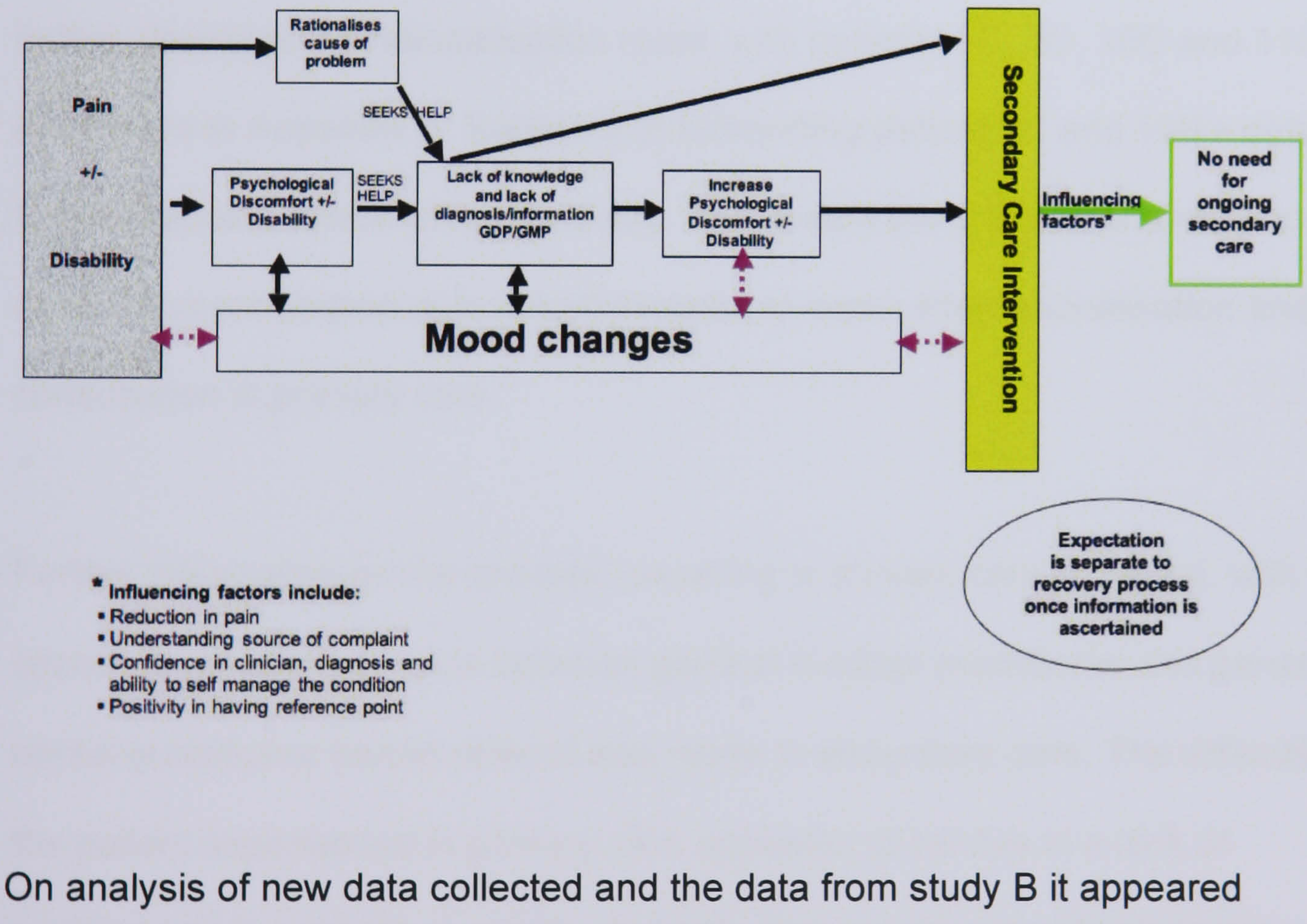
Further analysis of interviews conducted with patient sample C continued alongside re-application of the current map (v3) to each patient (Study B & C). As interviews and analysis continued it became apparent after the first four interviews that it was possible for patients to rationalise their complaint to a particular cause. This ability in some cases enabled the individual to avoid the initial anxiety over the origins of their complaint. Moreover it appeared that the term, "anxiety" was being used inappropriately within this map and what patients were alluding to was psychological discomfort/disability over the source of their complaint.

Patients 1C, 2C and 4C all seemed to rationalise the source of their complaint and their paths and data are contained in Appendix 3. Patient 2C, however, appeared to deviate from the proposed path and was flagged alongside patients 6B and 10B whose paths were very similar. All rationalised the source of their complaint, but then reportedly failed to receive a diagnosis in primary care, with 2C and 10B reporting further psychological discomfort after this.

The major change in map version 4 was to allow for this possible rationalisation (Map v4, Figure 5-6), but it was felt that this rationalisation path

needed further data. The data from patients' 2C and 6B was re-examined and this helped inform the topic guide. Interviews from this point onwards probed further into patients' possible rationalisation and their progress from the point of diagnosis. The a priori route for patients who required no intervention and had undergone no psychosocial effects was found to be unsubstantiated by the data and was removed. This is probably due to the nature of the sample and is discussed further later (Section 5.4.5).

Figure 5-6 - Map v4 - Changes made after analysis of first four interviews in Study C



On analysis of new data collected and the data from study B it appeared invalid to pass comment on the type of intervention required in secondary care for the patient due to the path they had taken. It became evident that it was more appropriate to rename that point on the pathway ("Minor or major

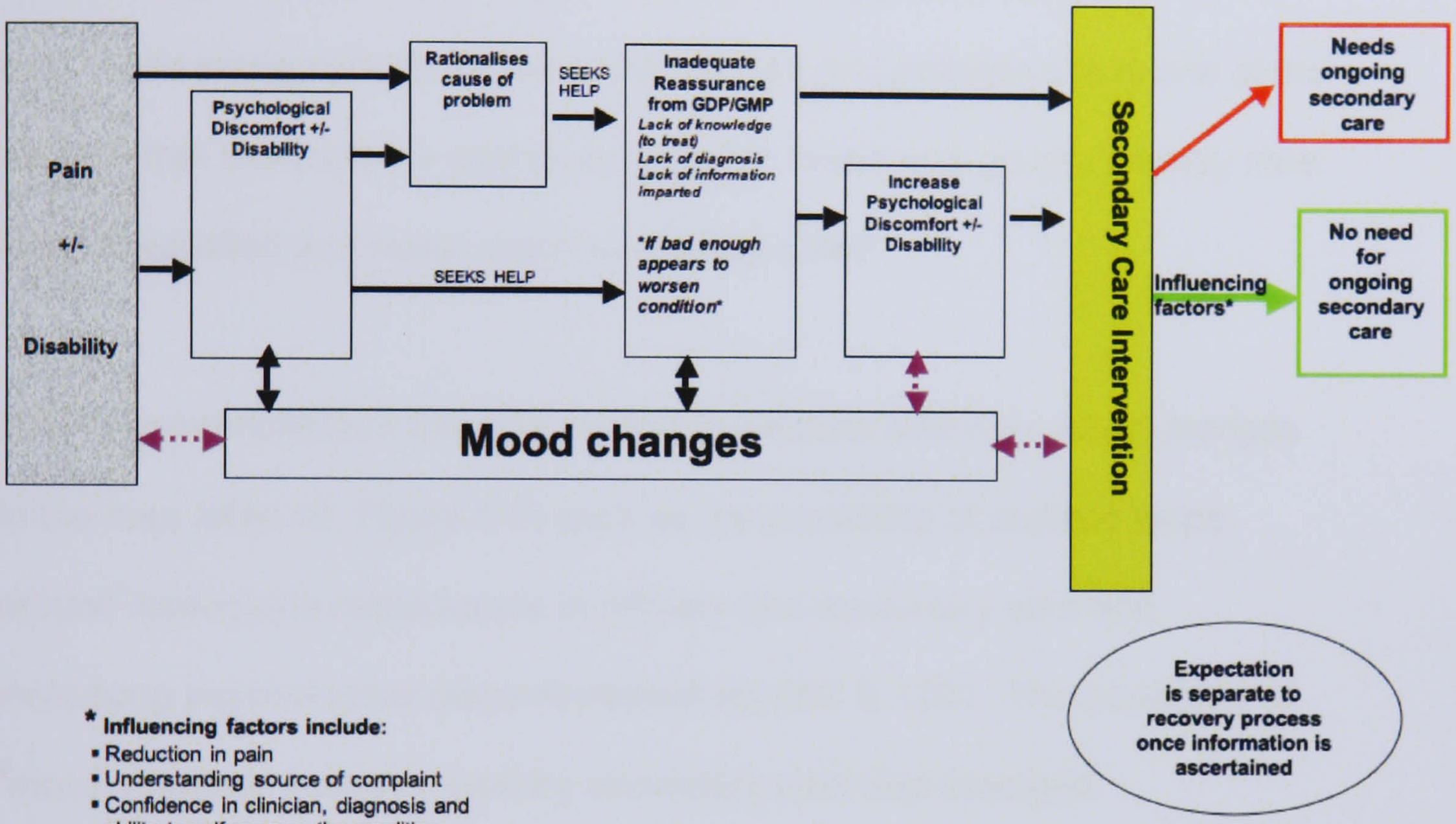
intervention"), "Secondary care intervention". Within secondary care intervention the combined data from study B and the first four interviews of study C made it valid to reintroduce the amended influencing factors (removed from map v1), on the patient's need for ongoing secondary care. It was noted that there must be patients who still require ongoing secondary care, indeed patient 6B appeared to support such a path, and therefore steps were taken to identify such patients to interview.

Map version 5 followed further in-depth interviews with cohort C and was supported by the new and existing data (map v5, Figure 5-7). Map version 5 further develops the rationalisation route, with patients 5C, 7C, 10C and 11C (Pathways in Appendix 3, Section 8.2) supporting patient 2C and 10B's data, flagged deviant cases from previously. This meant the creation of a route to allow for psychological discomfort/disability to occur after rationalisation and consultation in primary care.

Further information on the process occurring in primary care emerged, with it appearing possible to cycle between general medical practitioner and general dental practitioner before referral was made to secondary care. The difficulties the patient experienced in primary care appeared to be due to a lack of professional knowledge in relation to TMD. This resulted in patients lacking a diagnosis, treatment for or information on their condition which all impacted on the patient in different ways. The identified difficulties were added into the map, but this was done for ease of analysis only, as it was felt the lack of

knowledge central stage may need simplification in the final map to "Primary care" and separate notes be made on the processes that can occur within that stage.

Figure 5-7 - Map v5 - Changes after twelve "C" interviews

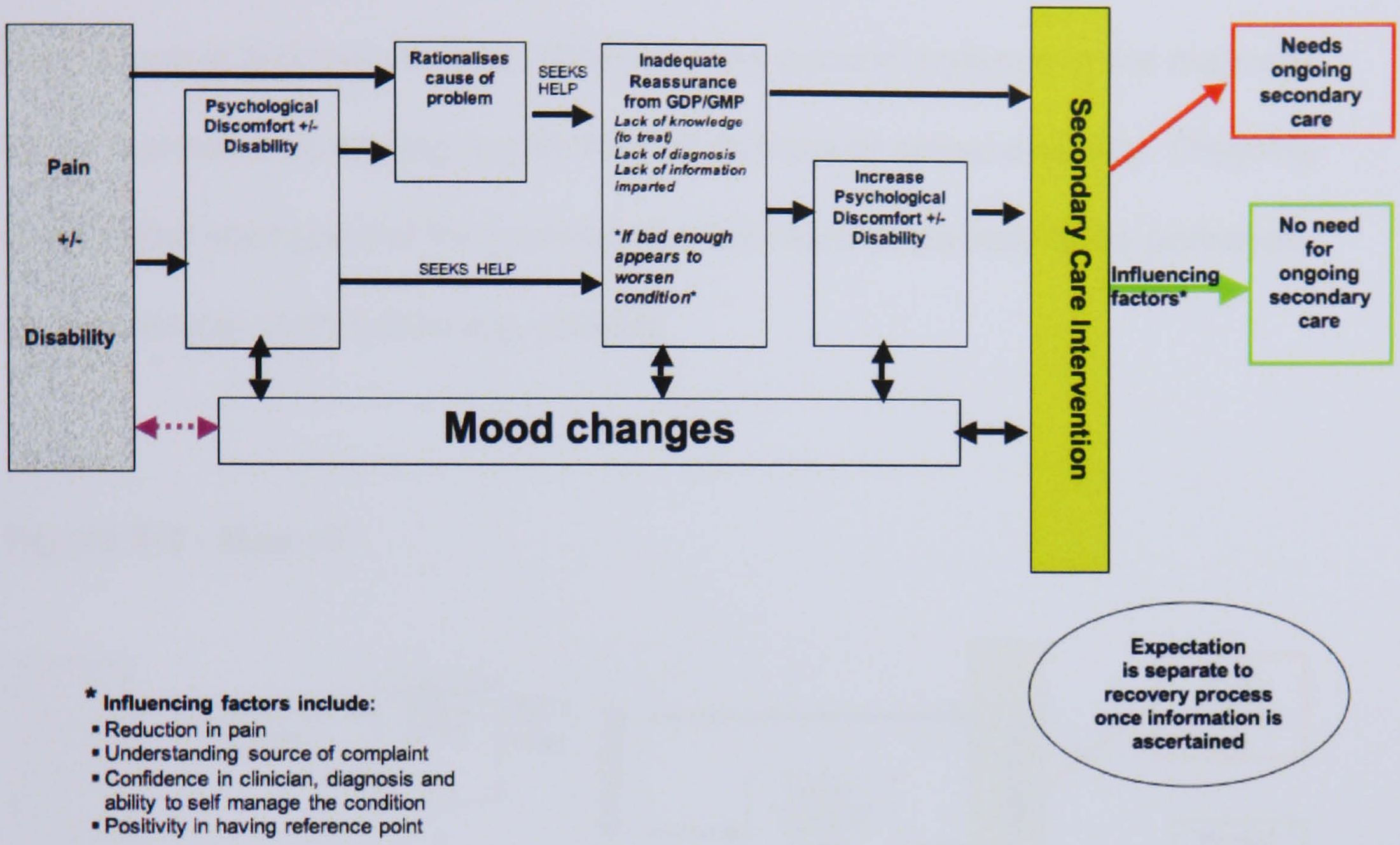


Patient 8C's data along with patients 12C and 6B (Appendix 3), implicitly suggests they require "ongoing secondary care". This need seemed to be created by a number of factors. It is likely that for 8C and 12C it was exacerbated by the levels of psychological discomfort or disability created by

the multiple misdiagnoses and mismanagement they have received. Further to this 8C remains unconvinced of the origin of her pain and still worries about it. She also provides evidence that misdiagnosis in secondary care may cause increased psychological discomfort and thereby a cycle in the latter part of the pathway. In the case of patient 6B, her complaint was low-grade on presentation, so much so she did not feel as though she needed to be referred, and this has not changed. It could be suggested therefore that this was not disabling enough for her to be referred and perhaps she is one of the patients that this pathway cannot account for, those who go into primary care and are satisfied and never reach secondary care?

With ongoing collection the map started to saturate with only minor changes to the map (Map v6, Figure 5-8) such as the possibility of multiple loops around inadequate reassurance in primary and secondary care and increasing psychological discomfort/disability (8C & 12C). The possibility of "mood changes" being caused by secondary care also emerged.

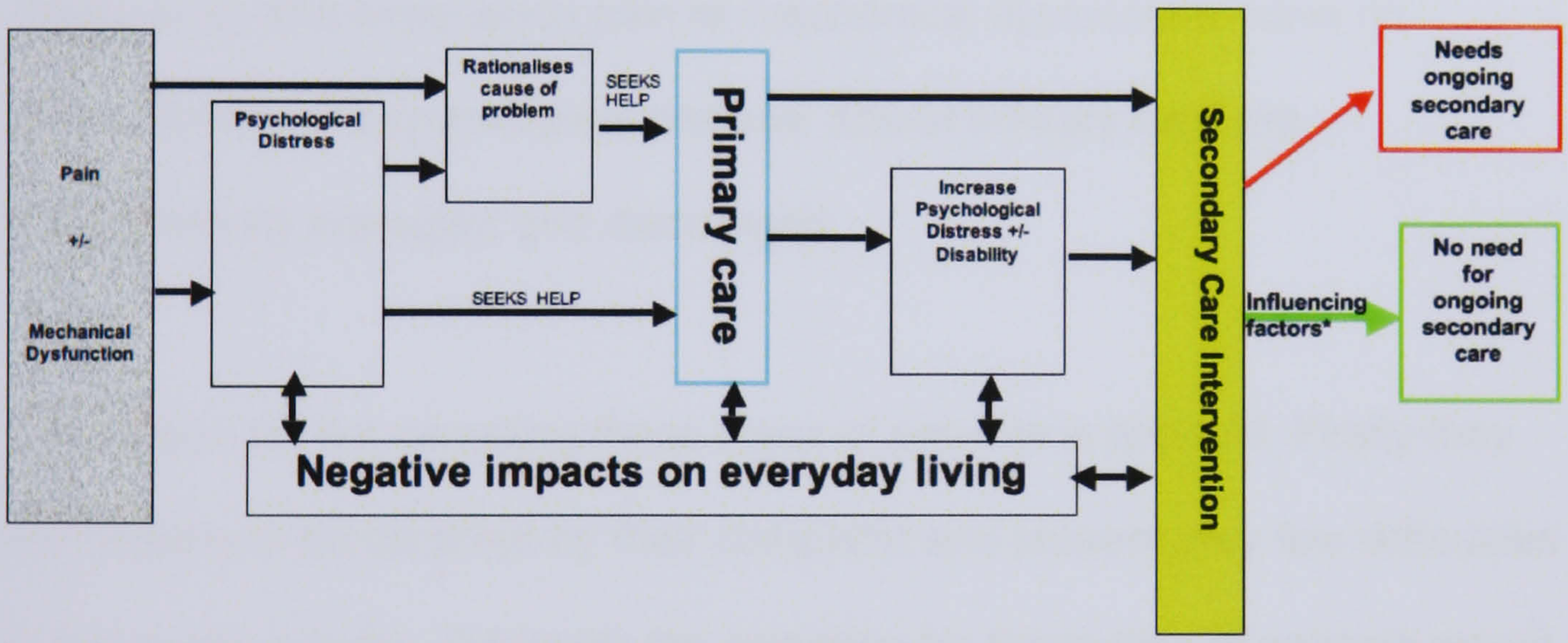
Figure 5-8 - Map v6



By patient 19 of cohort C the map was saturated (Map v7, Figure 5-9) with only changes to wording appropriate: “mood changes” to “negative impact on everyday living” and “inadequate reassurance” to “primary care”. These changes were determined to be more inclusive of the varying processes that could occur within these stages; for example, patients could start to doubt the legitimacy of their complaint during their journey for obvious reasons. This appeared important to their journey but was not a mood change and the more generic and encompassing term “negative impact on everyday living” became apposite.

The expectation part of the map was removed as it was felt that this can be stated and it had no interaction on the pathway. The first occurrence of psychological discomfort/disability was felt more accurately to be psychological distress (Ridner, 2004) and the second instance in the map was felt to represent worsening psychological distress or actual disability. Disability at the initial start point of the journey was felt more accurately to be portrayed by mechanical dysfunction e.g. clicking.

Figure 5-9 - Map v7



* **Influencing factors include**:
- Reduction in pain
- Understanding source of complaint
- Confidence in clinician, diagnosis and ability to self manage the condition
- Positivity in having reference point

5.4.5 Critique of map through care

The criticism of the map through care relates to its sample and has been briefly touched upon previously. Purposive samples are not representative and therefore are not generalisable to a wider population. Data found can only really be applied to the type of sample drawn and this leads to the critique that I have only sampled secondary care patients. This, I acknowledge, is a limitation of the study as there must be patients who: a) don't even present to primary or secondary care, we know this from presentation data (Gray et al., 1994); or b) who experience pain or mechanical dysfunction, have no rationalisation or psychological distress, attend primary care are conservatively managed and discharged.

The reason for not sampling these types of patients is two-fold. Firstly they are unlikely to be disabled by their complaint and present very few difficulties to the health-service. Secondly the sampling for these type of patients would be near impossible as when I discussed the matter with a number of local general practitioners they were unable to recall these type of patients nor indeed were their data handling systems able to search for them.

The only other critique of the sample is that I did not sample individuals with co-morbidities who might have differing perspectives as they may struggle to

achieve mastery of multiple conditions. This decision was taken because it might have made the analysis less specific to TMD and more difficult to attribute the reports of individuals specifically to TMD. Finally, I did not include socio-economic status as part of the criteria for the purposive sample. Given the personal knowledge of the sample that I have I would suggest that a broad range of socioeconomic groups were incorporated within the sample. I do not feel, therefore, that the data loses any validity for the fact that I did not formally classify individuals included.

From a health services research point of view, we need to target those individuals who are undergoing unnecessary exacerbation of their complaint and therefore presenting more frequently, requiring longer management and can give specific information on TMD that will help with our management of the condition. I feel, therefore, that this sample achieves this.

5.4.6 Summary

Within the data discussed (Section 5.3) and the map outlined, there is a patent recurring problem, a lack of a clear informed diagnosis at stages of the journey through care. From the data it is possible to hypothesise that if a clear diagnosis were given at the point of initial contact with the health profession this may then decrease the progression of the illness.

The diagnosis, however, as has been shown in the data (Section 5.3.3) has to be given with confidence and this is where problems can also occur. It appears that due to the uncertain aetiology of TMD, professionals are hesitant in giving diagnosis but also are hesitant in issuing it with authority (Sections 5.2.3 and 5.3.3). This impacts on the patient's confidence in the diagnosis and can therefore still lead to psychosocial effects. Professionals in primary and secondary care must be aware of the importance of affirming diagnosis with certainty and must always seek to re-affirm a correct diagnosis given previously.

Alongside the lack of diagnosis there is an issue with a lack of public awareness of TMD (Section 5.3.3). This leads directly and indirectly to the possibility of felt stigma, lack of belief in the "unconfident diagnosis" and psychosocial effects. TMD needs to be publicised, with care, to society as a whole to help increase its perception as being, on the whole, benign and self-limiting. This will help reduce the incorrect conceptualisations of the pain, the social disability, the information control and any felt stigma it causes. It will help increase the individual's legitimisation and belief that the illness can be managed. It may paradoxically increase its presentation, as according to its presentation patterns (Gray et al., 1994) there are large numbers of individuals with signs and or symptoms who do not present for treatment.

Clinicians need to be aware not only of the wider parallels to the psychosocial phenomena that have the potential to occur with TMD, but also the

effectiveness of self-management techniques. Within the data those who consider they no longer require secondary care clearly indicate in their reports the subjective efficacy of these techniques and these need to be investigated further with TMD patients.

There are a multitude of chronic illnesses in dentistry that clinicians routinely struggle with and may label as heart-sink. This map through care and its accompanying literature review show that it is possible, with a wider viewpoint, to find research that helps with what sometimes seem insurmountable clinical problems

6 Conclusions

This thesis reports on a series of studies aimed at understanding the psychosocial consequences of TMD and the ideologies behind their management. The first of the listed objectives of this thesis was to identify the ideology and rationale behind the management of TMD. The primary ideology appears to be “to do no harm” and the rationale for practice is based foremost on this. Decisions on individual management techniques appear to be determined by experience rather than evidence.

The second objective of this thesis was to investigate the psychosocial consequences of TMD for the sufferer. The psychosocial consequences appear varied and mostly determined through lack of diagnosis and uncertainty over the cause of the complaint. Individuals with TMD clearly experience impacts that can be related to the perspectives of TMD expressed by the professionals. One of the indications of this is that the patients consistently report the lack of a clear-cut diagnosis when they are seen in primary care. Professionals do not appear to be particularly aware of the psychosocial effects of TMD, the importance of them to the sufferer, their part in their development, or the need to manage them.

The final objective of this thesis was to develop a conceptual map of patients’ experiences of, and journey through, care. Patients’ journeys through care appear to conform to a reproducible map, and the journey they undertake

appears to contribute to the individual's general uncertainty. This uncertainty appears to be worsened with more inter- or intra-speciality referrals without a diagnosis. The map through care highlights that if adequate reassurance, diagnosis and reversible therapy were given in primary care there might be the potential for a decline in the need for secondary care; this, however, needs further testing.

This thesis highlights the importance of the psychosocial effects of TMD and their role in perpetuating the disruption it causes to day-to-day functioning. It is important that these effects are recognised and dealt with in order to allow individuals to adapt to TMD. Without recognition individuals continue to lack legitimacy and sometimes they experience a worsening of the effects of the condition.

7 Recommendations

For clinical care

Temporomandibular disorders are a complex area and their management is in the main, rather idiosyncratic. There is a clear need for better quality evidence on which to base practice and one of the keys to generating this evidence is a valid and reproducible patient based outcome measure that captures the variety of psychosocial effects TMD can exert on the individual. There are three main recommendations for clinical care:

1. There is a need for straightforward educational programs/interventions aimed at primary care, designed to give dentists confidence in the simple steps of diagnosis and initial management of TMD at a level that is appropriate for the environment in which they work.
2. The map, and the thesis in general, highlight the importance of comparisons with management strategies for conditions outside of dentistry that might be considered chronic illnesses. Of the many useful comparisons, one of the more important is the possibility that self-management programs might be efficacious in TMD in the way they have been used in other chronic illnesses such as arthritis. This requires further investigation as, if patient led self-management groups were found to be useful in TMD, this may help with time-constraints in both primary and secondary care.
3. There is a need for a reliable clinically applicable diagnostic index that is practical for use in primary care. This index, on completion, must

make a diagnosis immediately apparent, unlike the existing standard research diagnostic criteria, which requires lengthy algorithms to be completed. Work towards this index has already been undertaken in an MSc running parallel to this thesis that I co-supervised (Hasanain, 2007). It has produced a shortened version of the Research Diagnostic Criteria that gives an immediate and understandable diagnosis for primary care practitioners. With familiarity it can be completed in less than six minutes and has demonstrated moderate to substantial agreement with the Research Diagnostic Criteria.

For further research

Further research resulting from this thesis centres on further testing of the map. This might be achieved by using a clinical trial. The design for such an approach would need careful consideration but the intervention might include a period of targeted training in TMD diagnosis and management for primary care practitioners. Primary care dentists could be trained to manage TMD in the conventional reversible manner and also to facilitate patient led self-management groups. The outcome would be simpler referral patterns and possibly patient based outcomes. Concurrent qualitative research to unpick the mechanisms underpinning any changes (or lack of changes) in behaviour would also be required to inform the implementation of findings.

The map through care might be useful as a conceptual framework for the development of a patient based outcome measure. Given that OHIP uses Locker's model of oral health (Locker, 1988), which is based on, the now superseded, International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980) the map might be a reasonable suggestion from which to build a outcome measure. This needs further investigation as there may be two potential problems.

The first is that the new classification the International Classification of Functioning, Disability and Health (ICF) (WHO, 2002) is very similar to its predecessor and the key differences between them are that three levels of functioning are defined, and that ICF is more biopsychosocial than its predecessor. If the domains of ICF are compared to the domains of Locker's model of oral health it is obvious that Locker considered all of the biopsychosocial aspects of oral health that are now included in ICF. The question would have to be raised, therefore, is a new conceptual model required for an outcome measure to be made? The answer to this depends to a large extent on the distribution of impacts within the domains of OHIP-49 when it is tested with a TMD sample. This therefore requires further investigation.

The second potential problem is that the map through care was not conceptually intended to be a framework for the development of a patient based outcome measure. It may therefore have intrinsic failings in this

respect. It is also at present only applicable to the U.K. as it has yet to be tested in different countries and their health service provision may mean that it is invalid for their population. It therefore requires further testing.

Chronic illnesses in dentistry are common and often involve facial pain, for example, trigeminal neuralgia, atypical facial pain and burning mouth syndrome. It is possible that individuals with these illnesses may experience similar journeys as those individuals with TMD; they certainly represent a similar type of caseload to secondary care. These illnesses require further investigation to ascertain the individuals experience of them, their effects on the individual and the journey the individual takes to care.

8 Appendices

8.1 Appendix 1 – Topic guides and information sheets for all studies

8.1.1 Study A – Professional study

"Ideologies and outcomes in management of Temporomandibular Disorders"
Information Sheet for Potential Interviewees

Our sample has been taken and identified using the following criteria and methods:

- Oral and Maxillofacial Surgeon in District General Hospital – identified from the British Association of Oral an Maxillofacial Surgeons register
- Academics – Oral medic, Restorative consultant, Academic oral and Maxillofacial surgeon – identified from relevant professional society memberships
- General dental practitioner (GDP) – GDP less than five years qualified with no postgraduate qualification listed on GDC register and GDP greater than five years qualified – identified from General Dental Council Register
- General dental practitioner with specialist interest in TMD – identified from British Society of Occlusal Studies register

As mentioned previously these interviews and the ensuing paper will for part of a wider PhD thesis into constructing a patient-based outcome measure for TMD. The researcher is not being paid for this research. You can refuse to take part in the research or withdraw your consent at any time. If you withdraw consent for your interview to be analysed this recording and the written transcript will be destroyed and discarded.

These semi-structured interviews will take place over one hour with myself and are explicitly not intended to critique your practice; they are to gather enough data from a wide range of clinicians whereby we can accurately portray national practice in TMD. You will be encouraged to talk about your practice eg; your mainstay of treatment and how you define success, as much as is possible and I will ensure that the topic guide is covered by occasionally asking specific questions. The interviews will be recorded digitally and emailed to be transcribed by a professional company (Dataplus Solutions, Audio & Digital Transcription Services), once transcribed the recordings will be wiped from the recorder and computer. The hard-copy transcripts will be kept with an indication of your occupation and area of the country; no names will be retained with the transcriptions.

Once analysed the results will be published, possibly with literal quotes from yourselves however your identity and institution will be kept anonymous. The geographical area you practice in may be broadly identified if there are significant differences between the two areas, this being referenced as North or South of England as will the specialty you represent eg; oral surgery, general practice etc. Your practice and ideologies will not at any time be attributed to you and no reference will be included to the names of practitioners interviewed in the paper nor will your practice be reported to any external organisations.

The data will be used further to compare practitioners and patients criteria for success again your identities will be protected.
You will receive a copy of the signed consent form along with this information sheet to keep for your records

Should you wish to make further contact, comment or enquire re complaints or indemnity after the interview you may contact myself or the supporting Trust, Newcastle Hospitals Trust:

J.A.Durham
Restorative Dentistry
C/O Restorative Dental Secretary 3rd Floor
Dental Hospital
Richardson Rd
Newcastle-Upon-Tyne
NE2 4AZ
J.A.Durham@ncl.ac.uk
0191 2227828

Newcastle Hospitals Trust
R&D Dept.
Peacock Hall
Royal Victoria Infirmary.
Queen Victoria Rd.
Newcastle-Upon-Tyne
NE1 4LP

Topic Guide for Professionals

Opening question after introduction
Can you tell me a little bit about yourself and your dental training?

Perceptions TMD
Aetiology
Effects on patients and professionals
Common complaints, patients and professionals
Explaining TMD to patients

Management
Do you manage TMD?
If so why and vice versa
Whose responsibility is it to manage?
Role of primary and secondary care – *options for change, GDPs role and remuneration*
Role of MDT
How do they manage it – what do they do, where did they learn this, how have they been influenced
Rationale for management
The range of management styles used by others and their appropriateness
Knowledge of, and opinions on, evidence base
The role of private practice and whether this is different from NHS practice
Reasons for non-treatment

Success
Do they use outcome measures – which, how and why
Criteria for success – what is successful management of TMD?

Closing question

If you could send us away with one message for treatment of TMD, or a panacea, in your opinion, for treatment what would it be?

8.1.2 Studies B and C – Patient studies

Patient Information Sheet

"How your TMD symptoms changed over time and with treatment?"

You are being invited to take part in a research study, aimed to find out how your symptoms changed over time and with treatment. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?
Temporomandibular disorders (TMD) are a set of uncomfortable and painful symptoms either in the jaw muscles, jaw joints or both. This study is designed to explore the changes in discomfort and pain levels in treated TMD patients.

What are the possible benefits of taking part?
It is hoped that the information that is gained from this study may give us a greater understanding of the issues of pain and discomfort and their measurement following TMD treatment. We cannot guarantee that your participation in this study will be of direct benefit to you.

Why have I been chosen for the study?
Over the last few months, you have been treated in the Dental Hospital for the TMD problems you have been experiencing. You are invited now to take part in this study, which aims to investigate your own experience of such symptoms and problems, and how they changed over time and with treatment. Altogether 25 patients will be invited to participate.

Do I have to take part?
It is up to you to decide whether or not to take part in this study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at

any time, or a decision not to take part, will not affect the standard of care you receive in any way.

What will happen to me if I take part and what do I have to do?
As a part of your routine review appointment, we would like to invite you, on this occasion, to an informal discussion with the researcher. The discussion will take 30 to 50 minutes, and will take place in a quiet room next to the clinic. The researcher will tape record the discussion on a small portable tape machine. This is to make sure that we don't miss anything important.

Will my taking part in this study be kept confidential?
Your name will not be recorded on the tape, but we will make a record of your age and sex. Personal details and opinions you may express during the course of the discussion will be kept strictly confidential*. The tape recording will be kept in a secure manner in accordance with the provisions of the Data Protection Act (1998). The tape recordings will be stored in a locked cupboard with access only available to the researcher who has asked you to participate. The tape will be then transcribed and the recording will be destroyed within one year of the discussion. Afterwards, the transcriptions will be analysed, but will be coded so that we have no direct way of knowing which transcription belongs to which person.
The results of this study may be published in a scientific journal or presented at a research conference. In either case, your name will not be mentioned as part of the publication.

Who is organising and funding the research?

Who has reviewed the study?
This study has been organised by the School of Dental Sciences - Newcastle University, and is being carried out as part of a clinical PhD programme. It has been reviewed by Northumberland and Tyne & Wear Local Ethical Research Committee.

Contact for Further Information
If you have any questions please don't hesitate to ask either the interviewer or the consultant in charge of the clinic. The clinic consultants will also deal with any clinical issues arising in the interview.

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* Confidentiality will be assured as with all research of this type, except in extreme circumstances where information is received relating to certain criminal activities, and all participants should be aware of this before they reveal possibly incriminating information.

Study C - Topic guide to validate model and to ascertain new items for measure.

Can you tell me a bit about yourself and your family?

Can you tell me where you first looked for help with your jaw problem?
Looking for
- Who
- Where
- When
- Secondary referrals and chronology
- What they recall was said by each person

Can you tell me about your pain [same questions for click] please?
Looking for
- Pain Character
- Pain Duration
- Pain Site
- Effects on day-to-day living
- Anxiety caused by it
- Explanations given for it
- Pain affecting mood and how is it doing it synergistic, environmental etc.
- Need detailed info on starting point, progression and worsening/cessation
- *Testing your jaw/pain?*

[*If not already covered above* **- Can you tell me if your condition/problem has affected your day-to-day living and functioning?**
Looking for
- Eating habits
- Sleeping habits
- Work, not work, work patterns
- Mood, upset, anxiety and depression?
- Self-conscious?**]**

Before you spoke to anyone what did you think the cause of your problem was?
- Why did they think that
- Did that worry them or affect their day-to-day living

Who did you go to see first and can you remember what they told you?
- What information did they get from the healthcare profession and how did they view that
- What/who changed their mind and how did that happen

How was your mood throughout the problems you were suffering?
- Effects on nearest and dearest

- Effects on work
- Effects on socialising
- Effects on value of life

What do you hope your treatment will achieve?
Looking for
- Definition of success
- Level of expectation
- Percentage acceptance
- *Level to which they would go seeking a cure – Surgery?*
- *Concerns over legitimacy of problem and nos of consultations. ("I am a bother and there are people worse off than me")*

Do you think information helps with your problem?
Looking for
- Do they perceive a lack of it =>anxiety
- Did they get any
- Was it appropriate
- Was there empathy, if there was did this help the recovery, if not did it worsen?
- Did it help with self-help
- Was there any cancer etc phobias
- *Internet?*

What is the single most important thing we could do to help you get better?

8.2 Appendix 2 – Diagnostic criteria derived from RDC used for sample in studies B and C

Group	Criteria
	Muscle Disorders
Myofascial pain Key: Painful muscles	1. Reported pain in masticatory muscles [1] 2. Pain on palpation in at least 3 sites [2], one of them at least in the same side of the reported pain
Myofascial pain with limited opening Key: Painful muscles +limited movement	1. Myofascial pain 2. Pain-free unassisted [3] opening< 40 mm 3. Passive [4] stretch ≥ 5 mm (from pain-free unassisted opening to "painful" assisted opening)
	Disc Displacements
Disc displacement with reduction Key: Reproducible clicking	1. No pain in the joint neither reported nor on palpation 2. Reproducible [5] click on any excursion [6] with either opening or closing click 3. With click on opening and closing (unless excursive click confirmed): • Click on opening occurs at ≥ 5 mm interincisal distance than on closing • Clicks eliminated by protrusive opening
Disc displacement without reduction with limited opening Key: Limited opening with no clicking	1. History of locking or catching that interfered with eating 2. Absence of TMJ clicking meeting DDR criteria 3. Unassisted "painful" opening ≤ 35mm 4. Passive stretch <5 mm (from "painful" unassisted opening to "painful" assisted opening) 5. Contralateral excursion < 7mm ***Or*** Uncorrected ipsilateral deviation on opening
Disc displacement without reduction without limited opening Key: History of previously limited opening-imaging needed to confirm DD	1. History of locking or catching that interfered with eating 2. The presence of TMJ sounds excluding DDR clicking 3. Unassisted "painful" opening > 35mm 4. Passive stretch ≥ 5 mm (from "painful" unassisted opening to "painful" assisted opening) 5. Contralateral excursion ≥ 7mm 6. Optional imaging (Arthrography or MRI) to confirm DD
	Other Common Joint Diseases [7]
Arthralgia Key: Painful TMJ / no crepitus	1. Pain on TMJ palpation either laterally or intra auricular 2. Self reported joint pain with or without jaw movement 3. Absence of crepitus, and Possibility of clicking
Osteoarthritis Key: Painful TMJ + crepitus	1. Pain as for Arthralgia (reported and on palpation) 2. Crepitus on any movement ***or*** Tomogram evidence of joint changes [8]
Osteoarthrosis Key: Non painful TMJ + crepitus	1. Crepitus on any movement ***or*** Tomogram evidence of joint changes [8] 2. No reported joint pain, neither on palpation nor on any movement

1 In the jaw, temples, face, preauricular area, or inside the ear, at rest or function
2 There are 20 sites (ten on each side): posterior, middle and anterior Temporalis; origin, body and insertion of Masseter; posterior mandibular region; Submandibular region; lateral Pterygoid; tendon of Temporalis.
3 Interincisal opening plus overbite or interincisal opening minus anterior open bite.
4 Passive stretch: The examiner's index and thumb are used to moderately force the mouth to open wider than unassisted opening. Patients are instructed to raise a hand to signal when the stretch becomes too uncomfortable.
5 All clicks must be reproduced 2 out of 3 consecutive trials
6 Contra- or ipsilateral or protrusive
7 Erosion of cortical delineation, sclerosis of parts or all the condyle and articular eminence, flattening of joint surfaces, osteophyte formation
8 Erosion of cortical delineation, sclerosis of parts or all the condyle and articular eminence, flattening of joint surfaces, osteophyte formation

8.3 Appendix 3 – Patients' journeys plotted onto the map through care with representative quotes

This appendix contains selected patients' journey plotted on to the map through care. These individuals were selected as they particularly contributed to the evolution of the map as discussed in Section 5.4

Acronyms used:
GDP – General dental practitioner
GMP – General medical practitioner

8.3.1 PT 6B

When I had my six monthly check-up and my cheeks were sore (1A)

It had gone on about 18 … I mentioned it to the Dentist in December but it had gone on for about 18 months and why I mentioned that I was having trouble with my ears. I was having antibiotics for my ears and I just wondered, I said to the Dentist could it come from the jaw. And then he said oh I'll refer you to the hospital, Dental Hospital. I mean I hadn't … I said that it wasn't serious enough, you know (1B)

Well it was just that I was aware of it, you know, it was there. I was concerned but not constantly but, you know, every now and then within a week. But it was that I was having trouble with the ears, that was what prompted me to mention it to the Dentist (2A)

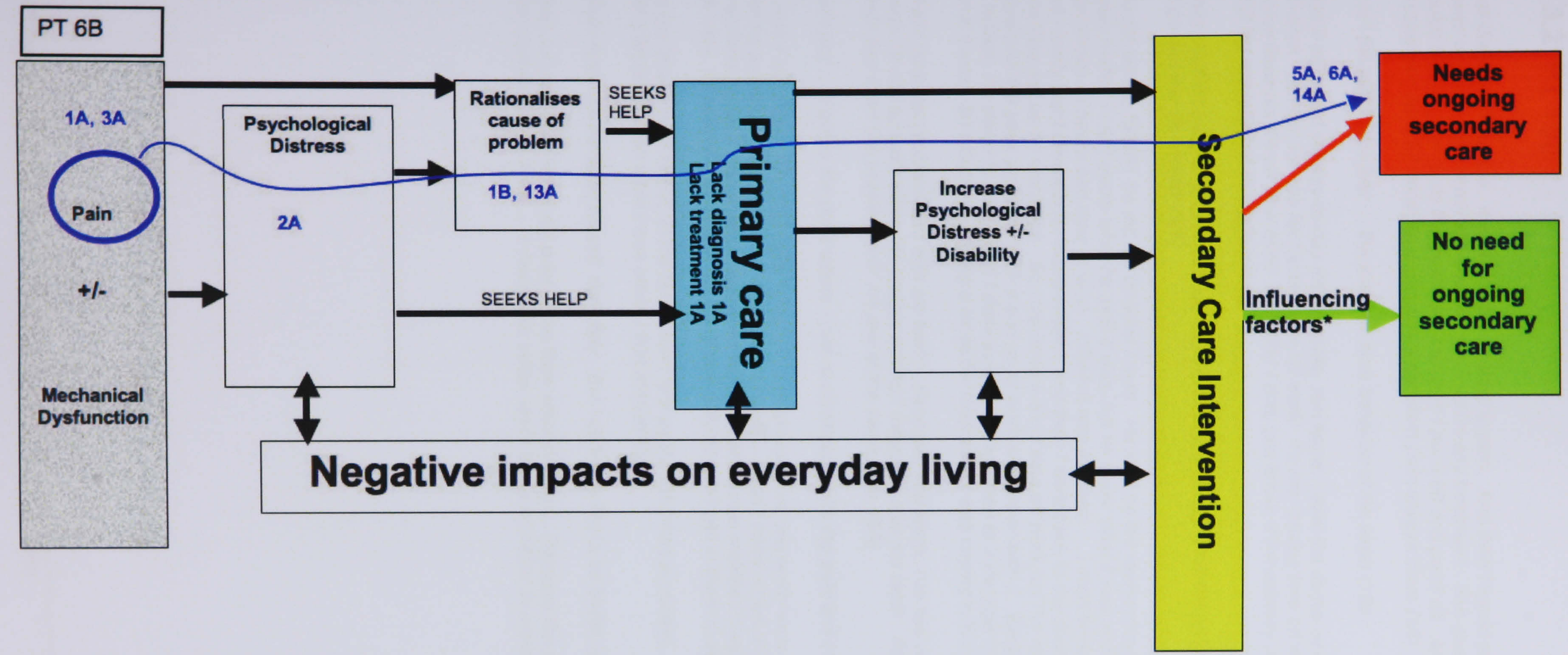
Yeah a shooting pain when it happens…Just like in me jaw like in my joints (3A)

No the same. I would say it's [the pain] just been basically the same since it started (5A)

Well I can't say … I mean like all exercises, you know, you start off that you're going to do them and you do them and then the next … by the time two weeks you think oh I'm getting dizzy. So, I mean, I can only be honest there. So I did do them initially but I can't say I found a big difference with them (6A)

I suppose it was when I was having trouble with my ears. You know, like an ear infection that had gone on for about 3 months and we couldn't get it sorted so I just thought it was worth asking the Dentist if this [her jaw] could have anything to do with it. So that was what motivated me really (13A)

Like I said I feel like a fraud because I'm not a serious case is it? (14A)



* Influencing factors include:

- Reduction in pain – Seemingly no reduction but then sees herself as fraud. 5A, 6A, 14A
- Understanding source of complaint
- Confidence in clinician, diagnosis and ability to self manage the condition
- Positivity in having reference point

8.3.2 PT 10B

Just the pain in me jaw. It was just like a nagging pain. And then I found when I had to go to the dentist it was on [name of a road] she couldn't get in to do any treatment. She couldn't get in me jaw…She couldn't get it open to do the treatment and then I put it off and put it off. And then I went to the doctor complaining about it because it was just a constant pain always there (1A)

And I thought it was just … the jaw was sore because of the teeth (1B)

Well it did affect my day-to-day life because, you know, I saw the doctor and the doctor said have time off work. But I'm not one for having time off work. To me, having time off work, is going to make it worse because it's on your mind 24/7. But I find, you know, if I'm actually at work, the pain's not there until I'm actually just trying to relax (3A)

They couldn't get it to open to do any treatment [did they say what the problem was?] Well they told me to go and see me doctor (4A)

He did tell us, [GMP], he did tell us what it was. He said he felt really sorry for us because the pain's really there. I can't quote what he said it was, but he knew what it was and then he sent me to see somebody…I had a bad time at work. I think it was involved … I don't know what went wrong at work, but I really went downhill for some reason, and then I went back to the doctor and he sent us up here and they put us on morphine. So I did have a bit of time off work but I've realised now that you've got to cope with the pain, just cope with it and go to work and get on with it. Because, you know, I was taking 6 tablets, I'm down to 2 now and I think actually going down to 2 the pain is there but it's not as bad as what it was. So I think I'm coping a lot better than what I was coping with the pain (4B)

Well I think the problem was with me teeth. Because, you know, I've had a problem with me teeth since I was 19 and actually when me teeth's aching I thought it was me teeth. So I had a problem with me teeth and I had the problem with me jaw at the same time. (5A)

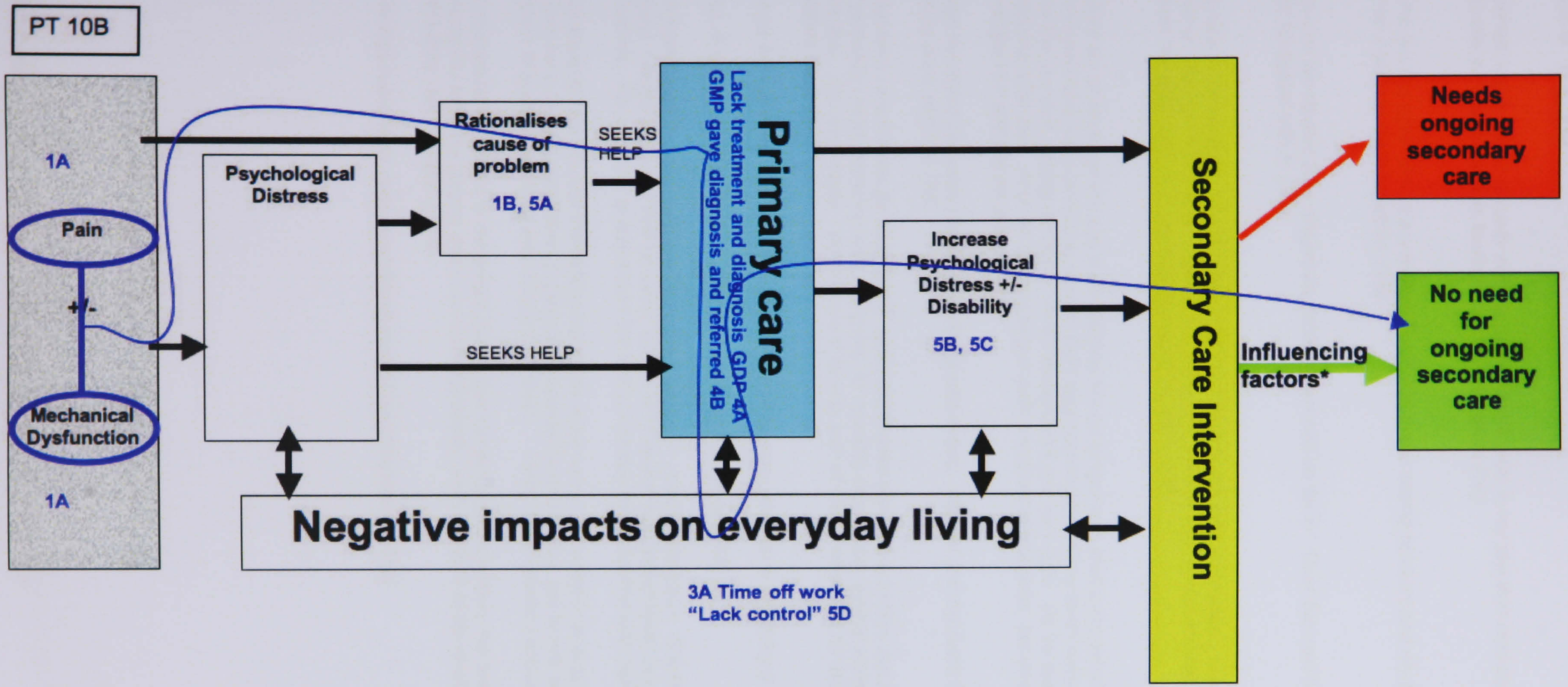
but I just … it got to the point where I just couldn't cope with the pain and I was on the sick (5B)

I think I had the problem at work because me jaw was sore, me teeth were going absolutely, I felt like getting a pair of pliers and, you know, but [tails off]…I didn't know where it [the pain was] was. I knew it was here [gesticulates to jaw area], but I didn't actually know whether it was the teeth or the jaw. And as I say, I'd been to the dentist and they said they couldn't get in there to do anything (5C)

At the time, I must admit, at the time I don't feel as though I was in control. But I'm definitely there now. I'm a lot better than what I was when I first started (5D)

Well I feel a lot better in meself, definitely. But I definitely feel a lot better, you know (10A)

Well, as I say, you know, it's a lot better than what it's been. Because the pain was terrible, you know, and sometimes … it just … it feels a lot better and I feel a lot better in meself (11A)



*** Influencing factors include:**

- Reduction in pain **10A, 11A**
- Understanding source of complaint
- Confidence in clinician, diagnosis and ability to self manage the condition **5D, 11B**
- Positivity in having reference point

8.3.3 PT 1C

I remember, it wasn't actually my jaw problem, the pain in my jaw that attracted my attention to it, it was actually an uncomfortable feeling in my bottom teeth (1A)

It felt like the right front of my bottom teeth was in the wrong position and my back teeth weren't fitting when I had my teeth together. (1B)

Went to the dentist for a diagnosis, "nothing we can do for it." Over the next few years, same problems, just struggled with it. (2A)

So when I opened my mouth it was sort of clicking to the left. And when I concentrated I used to get pain on the right hand side. Again I just ignored it, went to the dentist occasionally and just complained about my teeth and he'd say nothing could be done (2B)

About six or seven years ago a dentist that I'm no longer with took a mould of my bottom teeth because I was probably just convincing myself, but I was convinced that my teeth were actually moving forward and the jaw was getting set back. And I thought this just isn't right. So he took a mould and didn't do anything after that. And I'm starting to get quite annoyed at this point, but anyway nothing I could do, so just ignore it and get on with it (3A)

Well frustrated because I knew something was wrong. My jaw and my teeth felt wrong and nothing was being done about it. (3B)

First time I went there [to new GDP], again mentioned something to him, but nothing was done again. Eventually I kept pestering with just going for monthly check-ups, mainly scales and polishes and things like that. And eventually, I don't know if he was sick of me or what, but he took another cast of my bottom teeth (4A)

To be honest it was a dull ache. Nighttimes after wear and tear and talking it was kind of sharp. (6A)

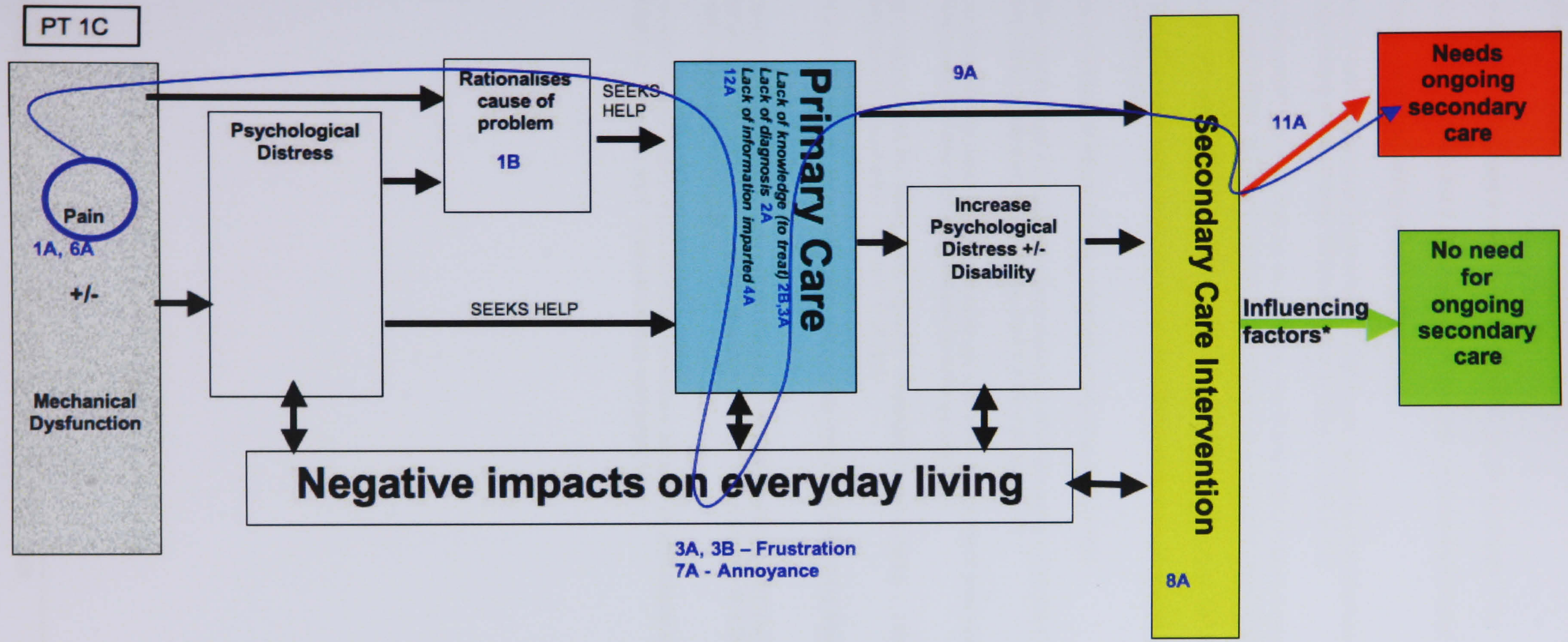
Yes, it wasn't depression or anything, it was just annoyance (7A)

Mr [consultant's name] told me Temporomandibular Joint Dysfunction. Got the sheet. He did mention about, I forget the word that he used, but he did mention the bottom teeth but said there wasn't a lot he could do. He could do re-alignment but that's probably unsuccessful with being an adult (8A)

Not anxious, no, no, just frustrating that there wasn't any … it wasn't causing me a great deal of pain, I didn't have to take painkillers, it gradually subsided over the day, got worse at night time after using my mouth to speak and chew and things, but never … I was never anxious about it (9A)

A successful treatment to me would be my jaw correctly up and down, the feeling that my mouth is big enough to take my tongue and I can speak properly, and my teeth to be re-aligned so that fit right. Just think they don't fit right. (11A)

Dentists have been very, very dismissive [of his complaints] (12A)



*** Influencing factors include:**

- Reduction in pain **6A**
- Understanding source of complaint – **fascinated by alignment 11A**
- Confidence in clinician, diagnosis and ability to self manage the condition
- Positivity in having reference point

8.3.4 PT 2C

It was like cracking and it used to lock. I couldn't move my mouth. (1A)

It was quite worrying but it didn't affect me that bad, I just wondered why it was doing it (1B)

It was a bit embarrassing when it locked. (1C)

I was at Wimbledon and my jaw locked and it was embarrassing because the people I was sat next to were looking at me strange because I was trying to unlock it (2A)

He (the GDP) just said that he wasn't sure why it was doing that so it might have been because I had a lot of work done before on my teeth and stuff and it could have been from that. (2B)

I was a bit worried because I didn't know what was going to happen [at the hospital] (3A)

I think they were going to tell me it was something really serious and I'd have to have an operation or something (3B)

It was just sort of discomforting, it wasn't a very nice feeling (6A)

Well I just thought it might have been because of all the work I had done and stuff because my teeth were really, really bad and … yeah, that's what I thought (7A)

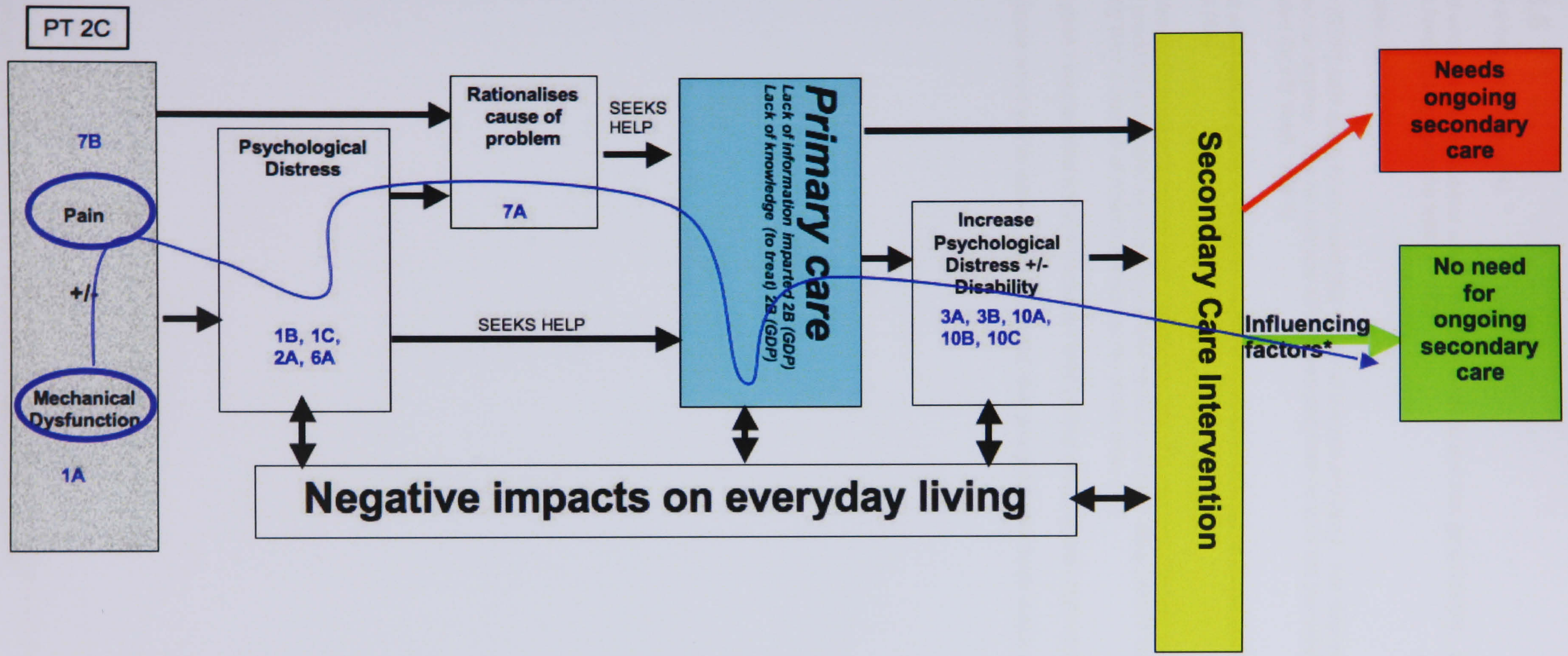
Just that it would make it trying to ease up and stuff and make it less painful, which it has done with those exercises and stuff and just being more careful (7B)

It just helped with the being more careful. Because I wasn't, I was … I didn't understand it so I wasn't being careful about what I ate and stuff (9A)

I'm like if it starts to get worse again then I have more understand on how to sort it out (9B)

It would have been a lot better [if dentist could have helped] because the word "hospital" is a bit worrying… The word like "hospital" is a bit worrying. Referring me to a Dental Hospital, I wasn't very happy about that (10A & B)

It would be very helpful if the dentists knew more about it as well because then he wouldn't have to send people up here and stuff. It would be less worrying (10C)



*** Influencing factors include:**

- Reduction in pain **9B**
- Understanding source of complaint **9A, 9B**
- Confidence in clinician, diagnosis and ability to self manage the condition **9A, 9B**
- Positivity in having reference point

8.3.5 PT 4C

Like a nagging pain. (2A)

[And what was your problem when you [first] went to see him [pt's GDP]?]…Well it was my jaw and I was keep getting earache with it (2B)

I'm pain free.(3A)

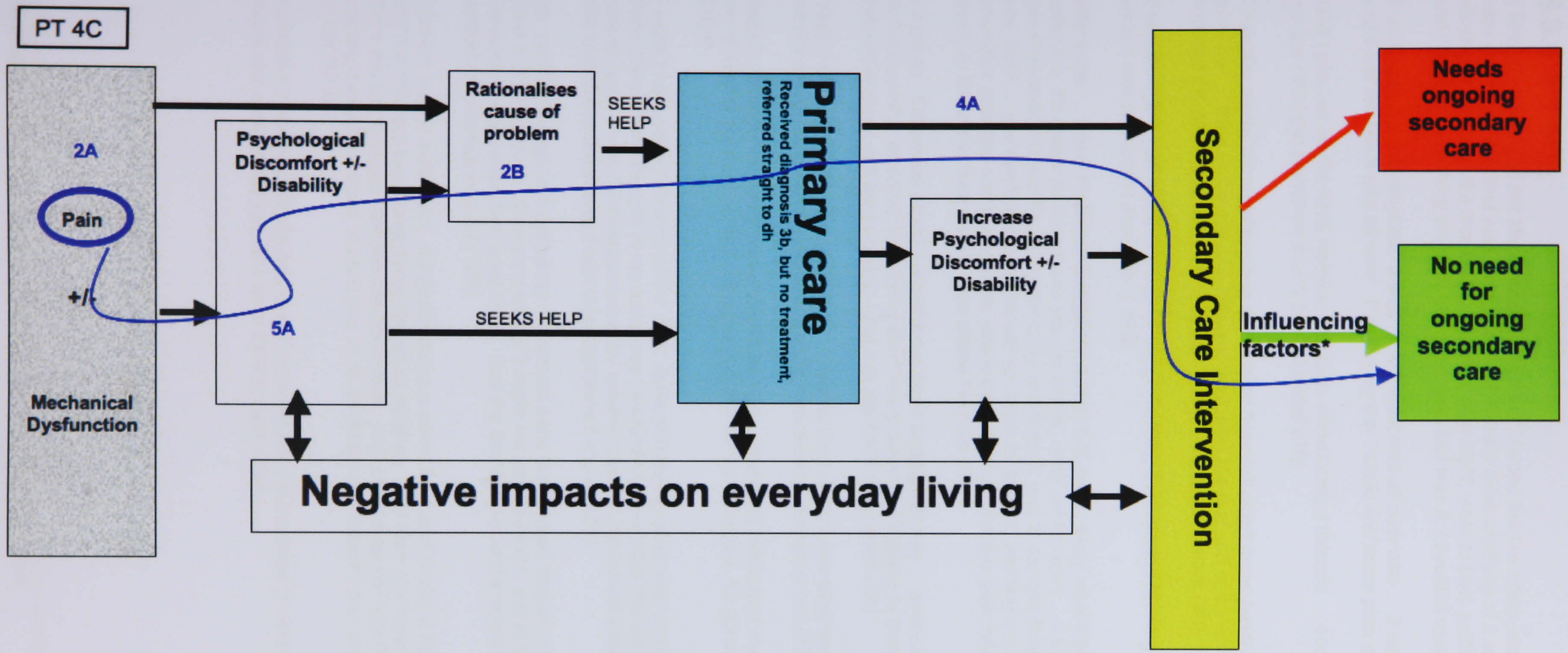
"He [GDP] said some funny word [the cause of the pt's problem]. I've forgotten the word now. It was muscular anyway…[So he told you what it was and then he said but you need to go to the hospital to be treated for it?] Yeah." (3B-4)

I felt okay [about going to hospital] because I just wanted to get it sorted out and see what the problem was (4A)

Professor [consultant's name] said, I would say about a year ago, he told us what it was and he started like prodding about and rubbed me jaw and he knew straight away what it was [How did that make you feel?] Well a little bit of relief but it hurt at the same time. (4B)

Oh yeah I was worried about it because I was getting shooting pain right up there, right up the side (5A)

Because when you're asleep, I've been told, that you grind your teeth when you're asleep (6)



*** Influencing factors include:**

- Reduction in pain **3A**
- Understanding source of complaint **6A**
- Confidence in clinician, diagnosis and ability to self manage the condition **4B**
- Positivity in having reference point

8.3.6 PT 5C

It kind of clicked and felt like it mildly locked but I forced the jaw open and it was fine. Like it clicked back into place and that was okay. So I didn't really think anything of it and it didn't feel any … no more clicking or anything like that until in January, one night, went to bed, putting my head back on the pillow and I felt like something dislodge in my jaw and that was it, I couldn't open it (1A)

It was really hard to pinpoint. It was … felt like it was all over one … it was just on my left side, not both, and it just felt like it was all over. Even in my ear I could feel some pain and no definite origin of it (2A)

Well I phoned up the NHS Helpline because immediately I thought … because I felt something shift in my jaw I thought somehow it may be dislocated (3A)

They [the dental emergency clinic at the local hospital] didn't know [what the problem was], they just gave me … they had a sort of a feel and they gave me that soft splint to wear. And they made sure I had that the same day and then they had a follow-up appointment (4A)

Because it [the soft splint] still wasn't doing anything they started thinking that maybe they didn't know what it was or couldn't deal with it. (4B)

Well once … when Professor [clinician's name] told me … likely what it was and kind of had a reason for what it is, it's easier to accept and you go alright, okay, well I won't … I know now not … that this is possibly what it is and therefore not to try and force it, just to eat soft foods. So you kind of compensate, you don't … you don't open your mouth as much for talking, you find ways around it. So you find that you relax your jaw and that's when, you know, you don't get any pain relief in that, it's just when you're trying to force it or over-use it. You notice the pain (6A)

I think so. Otherwise I think I would have been testing it to see … every day sort of going can I open it, is it still painful, whereas him saying don't worry about it, it's going to take a long time, just keep it relaxed and eat soft foods and so I put it to the back of my mind (7A)

Yeah I did wonder if … because they … initially they didn't know what was wrong, I … you don't know what's wrong. So you kind of do worry if it's something serious or not (7B)

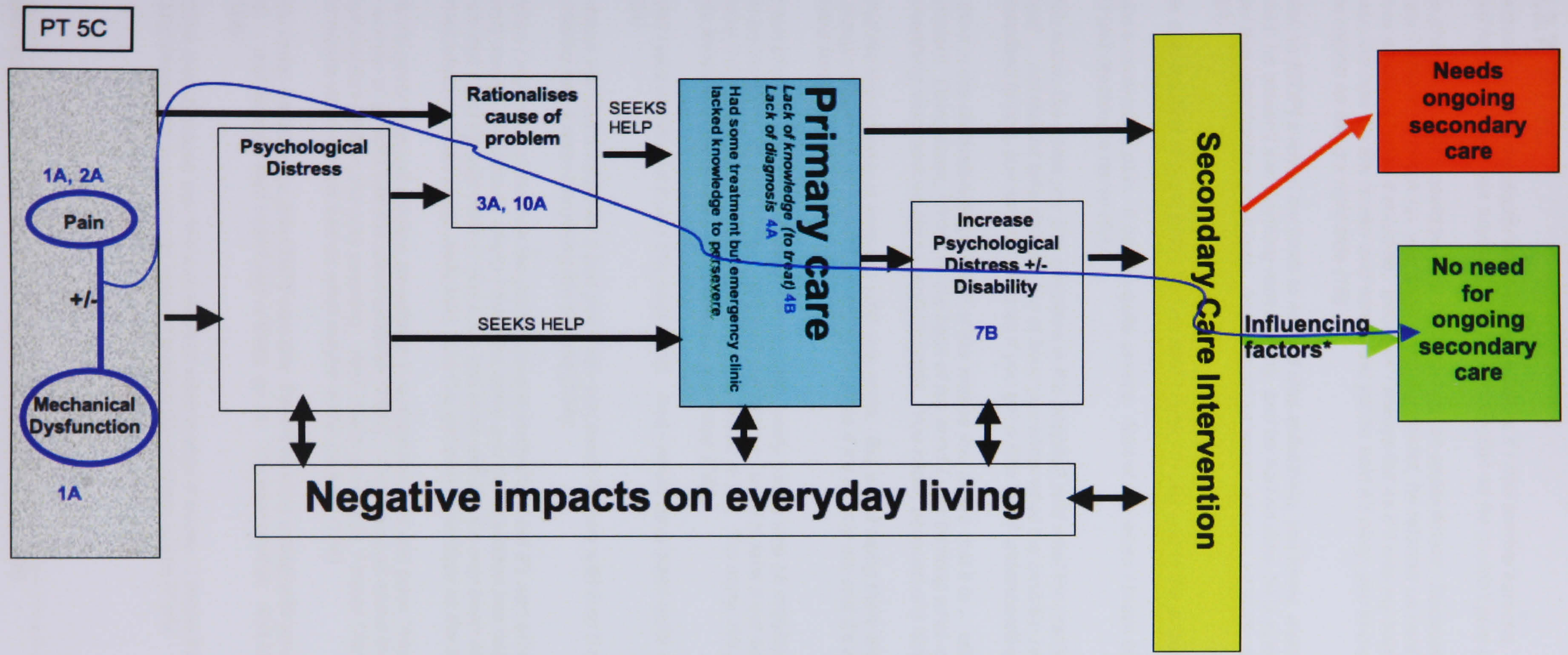
Initially I thought maybe it was a dislocated jaw. I mean I'd dislocated my shoulder before and I just … and it kind of felt a bit similar. So I just thought oh it's come out, it's gone back in, maybe that's what it is (10A)

I wasn't necessarily thinking of the cure, more of knowing what was wrong with the jaw. That was, I think, the primary thought in my mind was I wanted to know what this was. And then I think the cure was second. I was a bit concerned that I wouldn't get my movement back. It was just the initial finding out what the problem was I was most concerned about (12A)

He said that I might not get all my movement back but it would happen very slowly. And I was a bit … I think a bit, I suppose, stunned a bit that I might not get it all back, but at the same time any more movement was better than what I had. And the fact that he said it would take a long time, that kind of settled me down quite a lot (12B)

I think it helped quite a lot. It's good having a name for it and having a list of reasons that can cause it and the different symptoms that it can show itself as. And then also having the exercises knowing that there are some things that you can do to help. And also being told that it's not your fault, you know, it's nothing that you've done, it's just one of those things that happen and you just happen to be prone to it or not (13A)

I wouldn't come back [if she had the problem again], I'd just know to relax it and just go back to the soft foods, not strain it and just let it work its way back (13B



*** Influencing factors include:**

- Reduction in pain
- Understanding source of complaint **6A, 7A, 12A**
- Confidence in clinician, diagnosis and ability to self manage the condition **6A, 7A, 12B, 13A, 13B**
- Positivity in having reference point

8.3.7 PT 7C

I actually went to the doctor first because it felt as if I had terrible earache. And every time I went he said he could never see anything wrong. No infection so he couldn't give us anything (1A)

He [the GMP] said it could be your teeth so I put an appointment. Because I go every six months but it wasn't time for a check up, you know. And my dentist, he referred us here. Because he seemed to have an idea of what it could be. Because I always felt as if it was my back tooth on the bottom. I mean even like now it's like tender and sore. And yet he said it's okay, you know. So it seemed to be all in the region on like my right side (1B)

Well he [GDP] x-rayed my tooth to see if it was something, you know, a problem there. And he said whilst he couldn't see anything really wrong, and he had an idea, he'd said, you know, the facial pain and that what he thought it was. And he said he would refer us up to the dental to have it checked out (2A)

He said the kind of facial pain I had he said I think I'll refer you to the experts (2B)

Like a continuous pain. It can be quite severe. Sort of like when I touch behind my ear there it's just as if I was touching a nerve (6A)

You know, like when you [the clinicians in the hospital] said what the problem was, you feel oh well at least … not that I'd take it away, but at least you know what the problem really is and when it's described to you, you know, it feels as if you get a little bit of understanding about it (6B)

I think in the understanding it's sort of like makes you aware that it is … other people have the same problem. Deep down, I think, in the back of my mind I was thinking what is really going on, is it something more serious than I really thought. You know, because of it lasting for so long (6C)

Well the level of pain at times as well, you know. But with it being there like most of the time, you know, I thought it's got to be something wrong because if it's not my ear and it's not my teeth, it's got to be some sort of a real problem (7A)

It sort of made us, at times when it was really, really bad, a little bit irritable. People seemed to like get on my nerves a bit, you know. I felt as if sometimes I used to take it out on my husband a little bit. You know, I think you need to have someone, you know, to tell, "I'm sorry, I'm just having that much pain", you know, everybody sees the problems, you know (7B)

Well I was convinced it was this back tooth. And I would have been quite happy to have had it taken out (9A)

I mean you had a name for it and you knew you weren't alone with it so it eased your mind totally really knowing that it wasn't anything too serious (10A)

When I say most of the time the pain is always really there but it's sort of like times when it's ah really, really severe. And that's where I think the splint and the exercises has helped. Because the serious pain that I had I would think in about the last three months it's only been about maybe three or four times when it's been really really bad. But I've got pain most days all the time, but bearable (11B)

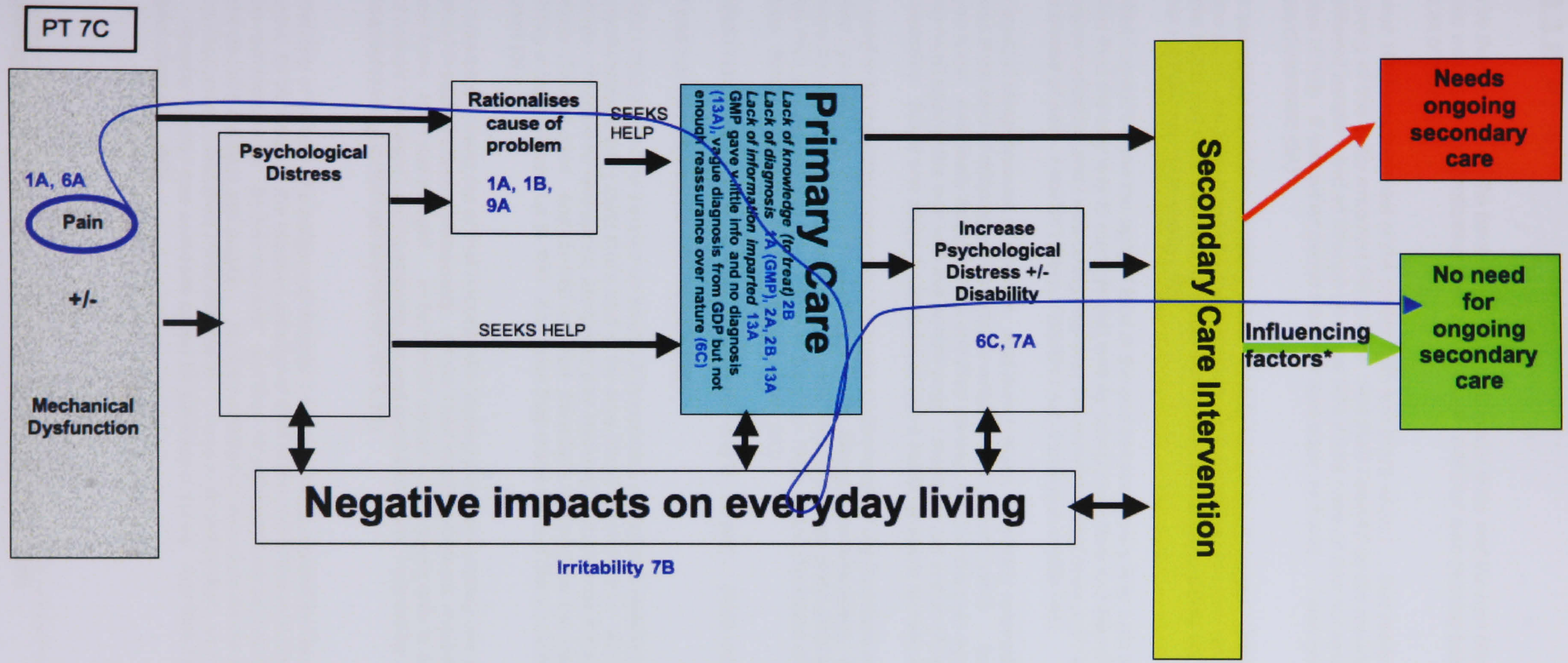
My daughter was just reading something in a magazine and she goes "hey mum look at this" and it was a woman of 64 who had the same problem [TMD]…And it was all about that and she was saying she had problems when she was yawning…Well, thank goodness, I mean I haven't had that problem yet. So maybe mine isn't as bad as what maybe some people (12A)

You know, because he [the GMP] was like, there's nothing wrong with you, you know. And I said to him but … and he says well I can't see a thing, go on. Try your dentist. And I thought dentist? For my ear? (13A)

I think okay because you find out yourself what makes it worse. I mean it's pointless isn't it, you know, doing things that you really do know is making the problem worse (14A)

It's something like … it eases your mind a little bit, you know. You realise that it's not anything too serious or you can put up with … well I can put up with it anyway (14B)

I just think the reassurance of yourselves [the hospital clinicians] and that, you know, really helped me personally…[the reassurance over] the actual problem, you know, and you've explained about the pain and the joint and everything. And I thought that was excellent. It really did help (14C)



* **Influencing factors include:**

- Reduction in pain **11B**
- Understanding source of complaint **6B, 6C, 10A, 14B, 14C**
- Confidence in clinician, diagnosis and ability to self manage the condition **6B, 10A, 14A**
- Positivity in having reference point **10A, 12A**

8.3.8 *PT* 8C

Yes the pre molar. The back molar. It was so badly done and the root filling that was done, the filling that was done was protruding over another tooth and that was causing pain and ever since then I've had a lot of pain (2A)

Well 1983 was the onset of the severe pain and that's when I … that really was connected, I feel, to having all this faulty excepted filling done. And then I started on the rounds of going to see all these different people. And all through up to the 90's it was more or less not really … I didn't really get a great deal of help. It was either dental work that was done, or it was … I was given drugs or diagnosis of psychosomatic (3A)

It seemed to be related to eating. And I literally lost so much weight. Literally I was on a liquid diet at one point. Because it seemed that whenever I eat something the pain would happen. Now, you know, that might well have been the movement of the jaw and stress building up, or, you know, I don't know, but I still get pain after eating (3B)

Well I couldn't stand the sight of food in the end because every time I ate something I was in this pain. And then the only way to manage that was by taking painkillers and then it became … the painkillers weren't effective and I was taking way over the recommended dose and I was just a walking, you know, a bundle of pain. I couldn't sleep, I couldn't eat, it was just terrible (4A)

I couldn't sleep because of the pain. And then I would … I literally remember times when my husband was there kind of dripping with a dropper whiskey on the tooth just to … because that seemed to help it, you know. And finally falling asleep and then waking up in terrible pain again and just literally banging my head against the wall with this terrible pain. I mean I'm not in that situation now, the pain's more controlled. But at one stage it was suicidal with it really, absolute terrible pain (4B)

I used to be the Administrator for the [name of business], a big [business name] and it was a lot of work. And I gave that up thinking that that might help. Being under less stress. But I didn't particularly have more time to think about it because I was finishing off a thesis at the time and my husband was doing his PhD so I was helping him. Still very busy but there wasn't the stress of dealing with people all the time. Which is often the biggest stress in here. (4C)

Well I was just in pain all the time. And not wanting to … I just … there was no joy in anything (5A)

I was just very depressed with the pain (5B)

And I think that's how I ended up seeing [Consultant's name] who decided I … you know, it was all psychosomatic and I think that's kind of the area [they] specialised in. And I was prescribed various drugs –Prothiedine Metropolol, Motipress and Meticerdi, I don't know if that means anything to you. All those different ones. And the first one that [clinician's name] gave me, the Prothiedine, started off at 25mg a day and went up to 150. And even they made me feel like a zombie. But that was my lowest point (5C)

I remember coming out of that hospital after seeing [clinician's name] one day who then tells me that [they] thought it was psychosomatic, maybe I had marital problems, maybe I should get divorced or … you know, and I just thought … in fact I don't swear, but I actually said to [them] "this is the biggest load of bullshit I've heard" and I just came out and burst into tears. I remember standing on the steps of that hospital thinking it can't get any worse (5D & 6A)

Well first of all they [the surgeons] thought it was just being caused by the pressure being exerted, you know, by chewing on the massive amount of stuff at the end of the root [the root filling extruded from the root filled tooth]. So that was that. But then Mr [clinician's name] and Mr [clinician's name] in the end decided it wasn't and maybe … but they couldn't do any more for me and that it could be psychosomatic. And then I was referred to … I was in [location] then, so I was referred to the General … Hospital where I saw someone called Mr [clinician's name]. And then I ended up going to the pain relief clinic in…. (6B)

Oh yeah. Mr [clinician's name] was the Consultant Oral Surgeon and I was under the care of Dr [clinician's name] first. And I was given Prothiedine. And then after that I was sent to the Atypical Facial Pain clinic. To the Pain Relief Clinic at [location], where I was Mr [clinician's name patient]. And he thought it might be due to some form of neuralgia. And … so he prescribed the drugs Moxipril and Motipress but I didn't respond to that. And Mr [clinician's name] did some kind of experiment. He inserted a sharply pointed dental tool between my teeth and brought the onset of pain on and then he actually injected with a large amount of Novocain but the pain didn't go away. So, you know, they said it can't be anything to do with your teeth. And then he referred me on to [clinician's name]. (7A)

And then nothing was done really [after all of her secondary care], but then I went to a local dentist in [location] where there was somebody called [clinician's name] and she did some treatment with braces to widen the dental arch and she also made this removable bite plate and that really started to help. And that was the first breakthrough. And then unfortunately I moved (7B)

Well I felt terrible, especially when my GP refused to refer me anywhere and told me I was a timewaster who was just imagining it. And, you know, not to bother him anymore. And then I changed my GP because I was so incensed about this. And then [secondary care consultant] more or less just said the same thing (9A)

Well Professor [clinician's name] said he felt that it had still not been satisfactorily ascertained whether the problem was a physical one or not. So he recommended that apicectomies were carried out. Okay, which they were done, they were carried out in the end. And that was in December '98 when they were carried out. (10A)

Well it was bliss. I'd found someone that would actually listen…..Because I just felt like a guinea pig being pushed from pillar to post and people saying "no, it can't be this because …" or "no it must be this because you're not responding to drugs, you're not responding to …" and all I knew was that I was in this terrible pain and I just … well to be perfectly honest I didn't know what to believe. And it was very difficult to maintain self-belief in the mist of GPs and a Leading Person at the [Name of dental hospital] telling me you're imagining it. You know, it was really, really tough (11A)

No. I was never concerned about that [being perceived as a fraud], I was just trying to make people believe it was legitimate. I think I was going in circles because if I said that I was in terrible pain and that's why I was depressed all [clinician's name] would say is you're depressed and therefore you're imagining the pain. So it was like chicken and the egg situation. I was just beating my head against a brick wall. Because there was this leading expert sitting there telling me this and I was just a layperson trying to say look I'm just in pain. That's why I wrote all this down because … maybe I wrote it down because I had to prove to myself I wasn't imagining it, you know (11B)

Yes because not only did she [specialist GDP mentioned in 7B] listen, but she was coming up with practical ways of actually … you know, and wasn't just drugs. You know, it was actually practical things that we were going to do and as we started the treatment and as the dental arch began to widen and the teeth were moved around a bit, the pain started to get less. And, yeah, yeah. I mean apart from the drugs I also sought some self-help I had some acupuncture and that didn't actually stopped the pain, but it helped me (12A)

I mean I feel tremendous sense of resentment against [clinician who told pt it was all psychosomatic]…I really do. I felt like she was quite … she did a lot of harm (14A)

I felt envy for everyone else. Everybody else being pain free. I remember I had a … I used to have these quotes and I can't remember who said it, but it was something like "enjoying life is being free of pain", something like that. And that was my mantra. You know, all I wanted to do was be free of pain (14B)

Well I still worry about it [the condition and its pain]. I still worry about it now because it's still with me. And even last night I'd be sitting there with the water and the painkillers. It hasn't gone away, and it still originates from these two teeth, and I still think that maybe … because maybe I should have the teeth out. Maybe it's still a dental problem. So no I still … I do, I do worry about it. And I worry about where it's going to go from here. As I get older and the problems become more acute (15A)

Well yes, at one point I had a … when I saw Mr [clinician's name and location], at one point I had a scan, a brain scan, to see if there was any abnormality. And I also had my, can't remember what they're called now, parotid ducts?...Examined in case that was causing it. I also had an examination of my

sinuses. So yes, yes. And I also, because of my … I have a lot of middle ear problems, I was concerned about the fact that my hearing was deteriorating and I was terrified that it was all connected. In fact I'm still not convinced it's not. Because I know I've got nerve deafness but I think the middle ear problems, my ears pop and … particularly when I swallow and when I chew. I still think that it is connected in some way. So, yes, of course. I mean I still worry about it. As you get older it's a worry about how … where it's going to flare up again (15B)

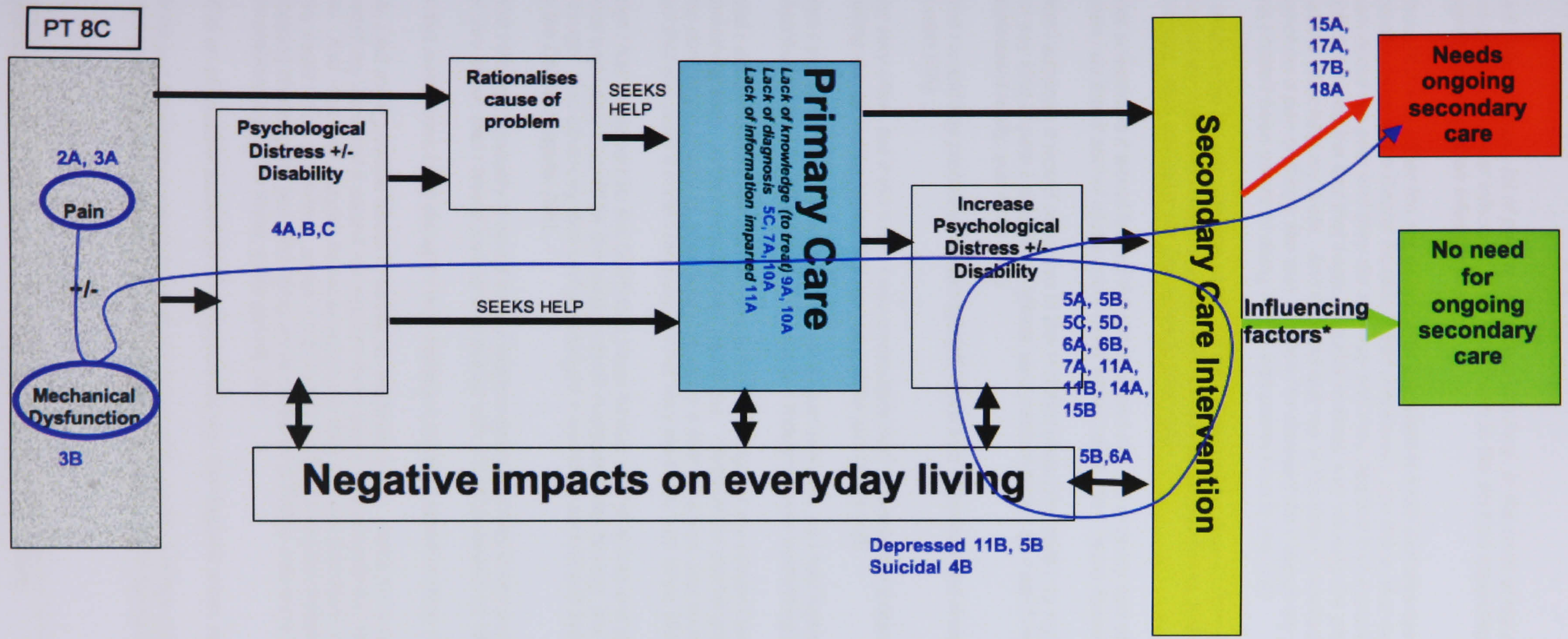
Well I've only got control now simply because I know I've had periods out of pain. I mean at one point between, I think, '86 and '88, was probably the lowest period, and that was just constant pain, 24 hours a day, every day of your life. You know, if that's all life is going to be what's the point. Whereas now, because it's managed with the removable splint and the exercises and when necessary painkillers. Brushing my teeth and flossing also seems to help, although that might be psychosomatic, I don't know. But, you know, things like that, I've got kind of walking sticks to get through, whereas before I had nothing (16A)

Well every time I eat I still get pain. And I suppose if that pain would go away within 5-10 minutes I'd be happy. These events persist for hours and hours and that is just, you know. I know that stress makes it worse because I do crunch my jaw and I do grind my teeth in my sleep. That's why the plate helps. But if I could experience a minimal amount of pain every day rather than hours of it, that would be great (17A)

I mean I have to say I am still not convinced that it is not something in the teeth as well. I know I've got the jaw problem, but I still … these two teeth in particular that, you know (17B)

Well I have to admit at the time when all this was happening I wasn't really given any information. I researched a lot myself and went through a lot of medical journals, you know, I read stuff. I don't think I was given that much. Maybe the odd sheet of an exercise to do. But I don't really think I was given a lot of information even now (18A)

Oh yes. Everybody likes to have a name for what they're suffering from, I mean, you know, even if it's a terminal illness at least you know what you've got, you know, you can come to terms with it more. But I think what I found difficult is that I've seen so many different people, you know, dental people I've seen, you know, psychologists, I've seen a chiropractor – I forgot to mention that. The acupuncturist. And everybody's really existing in their own little field. And I found there hasn't been a great deal of cross-over. And that sometimes in the problem described it is a number of issues that work. And it's not a joint attack, it's been that single-minded. And you're kind of pigeon holed and put in a box and sometimes I think right I would have benefited from if there'd been more sharing of information amongst the specialists and maybe a more all rounded approach whereas it's been very kind of … a single minded attack. And when that single minded attack hasn't worked then I've been dismissed and passed on to somebody else. And this has been going from pillar to post (20A)



*** Influencing factors include:** Pt has had some recovery and therefore shows some of influencing factors. Crux is that because of continuation of problem (15A), despite improvement she's still not convinced of her diagnosis (15B) (probably due to multiple diagnoses she's received or the continuation of her pain). She claims not to have had info on problem she has (18A) but obviously has by the depth of knowledge elicited through interview mentioned in relation to clinicians

- Reduction in pain **12A, 14B, 16A**
- Understanding source of complaint **20A**
- Confidence in clinician, diagnosis and ability to self manage the condition **10B**
- Positivity in having reference point

After all the secondary care (6 different clinicians in 3 different locations) pt found a specialist GDP who recognised TMD (7B)

8.3.9 PT 10C

Well I was having a lot of pain in the side of my face, in the back of my neck and head. And I actually thought it was an ear infection. And I had been to the doctors regarding the ear infection and thought I might have a bit of an infection (1A)

I thought it was either the ear infection or the wisdom tooth that was causing the pain. But when I actually came to the Dental Hospital I had mentioned, you know, that my jaw was clicking and then I told them about the pain and they did an x-ray and they decided that it probably wasn't actually the wisdom tooth but it was the fact that I was probably in some way causing the problem by, you know, grinding my teeth or clenching my teeth. And they did ask me at the time if I worked in an office where I might sit and chew a pen or things like that or when I'm stressed did I clench my teeth. And it was something that I hadn't been aware of doing until it was pointed out to me (1B)

It tends to be the left side [the pain]. Down the side of my face in front of my ear and it's also down the back of my neck and behind my ear. And it tends to be, you know, just an ache really and sort of stiffness. And obviously the jaw tends to lock (3A)

Well sometimes it would feel as if it's locked and I've got to really sort of jolt it to open it back up and when I do that it sort of clicks and it hurts when I do it. But I have found it a lot better of late (3B)

Well I suppose it would affect me in the fact that probably I didn't do my job to my full potential. If you've got any kind of pain I suppose it affects your performance. So I can't really say, but it just made it unpleasant really, you know (3C)

Well I would say probably I wasn't meself, more bad tempered and irritable, as you normally are if you're in pain (4A)

Not very often, but it did when I was particularly bad. I remember once for a couple of days it was putting me off eating because it was so painful just to eat (4B)

Well I thought it was my wisdom teeth or an ear infection, so I had been to see about my ears. And then I had been about my wisdom teeth because I thought it was something related to that (4C)

Well I did sometimes get worried, you know, thinking is it my wisdom tooth or is it my ears or is it something else…I don't know [what], you know. I think when you've got pain and something like that you don't know what it is, your bound to worry a little bit about, you know, what it could be. It's just the fact that you want it sorted because it's not very pleasant, you know (5A)

Well I had explained [to the GDP] that I was having a lot of aches and pains in my jaw and back of my neck and I said it could be the wisdom tooth because I was having, you know, signs of it coming through. And obviously that's what I thought it would be and he just said well look we'll get you referred to the Dental Hospital (5B)

Well I thought probably it would be my wisdom teeth and they'd say possibly that they needed removing or, you know, that I would just have to put up with it until it cleared up (6A)

In fact sometimes I just thought I was making a big fuss about nothing (7A)

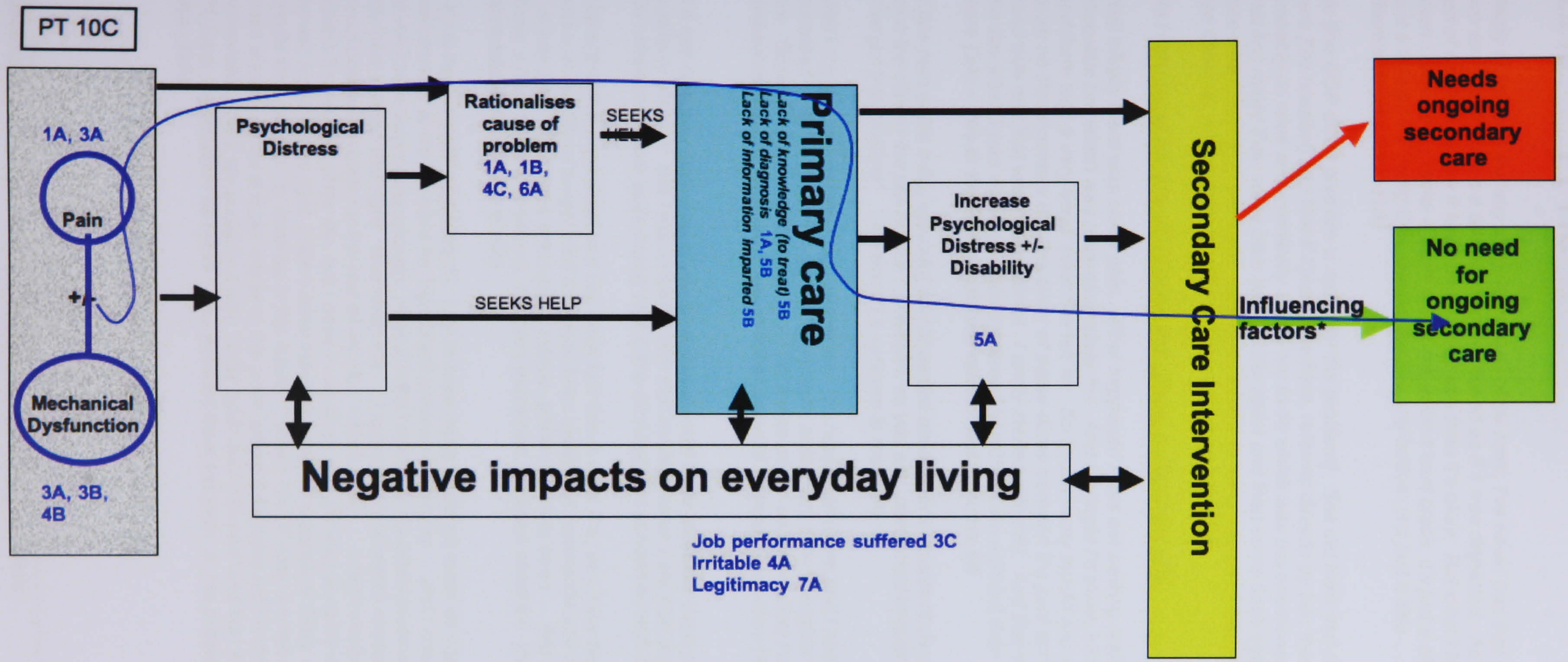
No, I felt more positive about it, because I realised that … well it put a label on what it was, I knew that it wasn't my ears and it wasn't my wisdom teeth and it was actually the fact that it was a problem with my jaw. And I felt a lot happier because obviously they told me that there might be some type of things that they could do to, you know , make it a bit better. Which even the things that he made me aware of – stopping chewing the pen and being more aware of grinding, you know, clenching my teeth – relieved the problem a bit, you know, quite quickly (8A)

8B is an affirmative answer to the question did you feel happier when you had a reference point?

I think just the improvements being more aware of it, avoiding things that can make it worse, and also I don't wear the gum shield all the time but I normally wear … I'm trying to wear it as much as possible.

But … I should wear it every night. But I know that if I've got the pain I put it straight in and I wear it to bed at night and it makes such a difference, definitely (9A)

My jaw still clicks, but I would say it doesn't lock as much, either, just the pain's so much better now (9B)



*** Influencing factors include:**

- Reduction in pain **8A, 9A, 9B**
- Understanding source of complaint **8A**
- Confidence in clinician, diagnosis and ability to self manage the condition **8A, 9A**
- Positivity in having reference point **8B**

8.3.10 PT 11C

Really not able to put any weight on it and chew hard, I've never had that sort of problem with it, just that now and again there's a terrible cracking sound as if it was disjointed. As thought it is out of joint. And sort of opened my jaw it tends to go away and then it's okay. But what I feel now is that sometimes, when I look for it, I make a slight crack, not even a loud crack, it's just a click, not even as loud as that. Just a little as I'm doing that, moving my jaw, my bottom jaw just a little … just like it's slightly out of joint. There's no pain there (1A)

No [the GDP didn't give him a name for the problem]. She did think that I'd eventually have to come here [the hospital] and that if I just came here, referred directly by her, then people that I saw here would probably do what she eventually asked me to do which was the exercises and the splint. So we tried that first rather than come here and get the splint and then come back again. So we tried that first and then when that didn't work she said right I'll have to hand you on to the Dental Hospital and see if they can come up with something different to what we've tried (2A)

No I can't recall her [the GDP] doing that [giving a diagnosis] (2B)

Well initially there was some pain. What happened I was out walking and we had a break and I had a chocolate bar which was covered in silver foil. And I thought I'd taken all the foil off the chocolate bar and there was a very small sliver like left on. So I put it in my mouth and just the way my luck is, as I bit down on the chocolate bar this sliver of paper came between the joint and my jaw went off to the right hand side and that was really painful. I really started with that. And that was quite painful throughout the day when I was walking. Then it seemed to settle down a bit but then I noticed the clicking was there (3A) – ***this is the initial episode referenced in quote 6A***

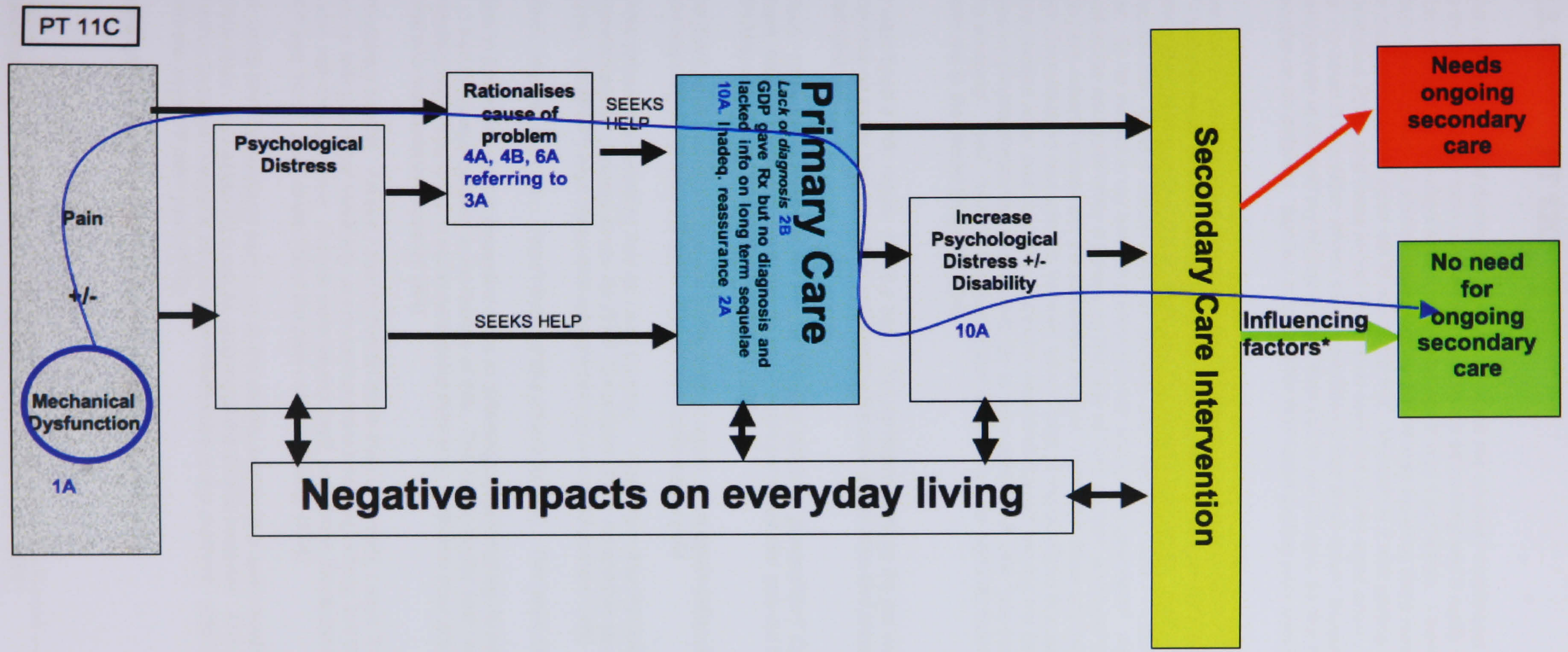
It [the pain of the initial episode] sort of settled down after a couple of days. And I felt as though I could hear the click in the jaw but it's … I wasn't, as you say, concerned enough to rush to the dentist and say "I've got this problem". That wasn't a concern to me. (4A)

Well I'd just … it's not a normal part of me. It's happened to me and I need to know if it can be corrected or what is the reason for it. Because at first, my initial thoughts were that I'd dislocated my jaw. Because when I said before that I felt it was all, on occasions that I've got as if my jaw has dislocated and I've moved my jaw round and sort of seemed to be okay (4B)

If it had suddenly come out of the blue then I would have definitely been concerned about why is my jaw suddenly clicking. But I associated it with that incident when I ate it on the chocolate bar [ref quote 3A]. So I knew that I was quite happy that it [the clicking] was concerned with that (6A)

I think that I've been seen and I've been told this is what it is, so I have been told what it is. That there was a possibility of surgery but it's never been really that successful and its not so severe that I needed it in any case. So I have been given advice, which is … has been … that I'm comfortable with. You know, it hasn't been dismissed, it's been examined, it's been checked. People have looked at it and have said this is what it is (8A)

I try to keep myself physically fit. I try to keep myself right as much as I can. For instance, I'm with my own doctors at the moment for high blood pressure. And I'm … and I know why it is, it's because I haven't been exercising enough. Now if I don't exercise my blood pressure gets worse, so I have to exercise to keep that right. And really it's … I suppose it's a selfish reason. I don't want to be taking blood pressure tablets for the rest of my life. I don't really … I didn't really want to be taking thyroid tablets for the rest of my life, but I have to do that. And if it was possible not to have this click so that myself, my jaw was right, I didn't have this, then yes it's a personal thing, I would like to get rid of it. Maybe it's because I'm thinking in the future. I mean I'm 57 now, if I was thinking another 15 or 20 years ahead, would this get worse to the point where it became painful and the pain became quite unbearable. So if we could fix it with 70/30 odds now the wear and tear that would get in the next 15 or 20 years just wouldn't be there. So I wouldn't have the pain, or the possibility of pain in 15 or 20 years time (10A)



*** Influencing factors include:**

- Reduction in pain
- Understanding source of complaint
- Confidence in clinician, diagnosis and ability to self manage the condition **8A**
- Positivity in having reference point

8.3.11 PT 12C

And I turned my head during the night and it woke me up and I swallowed at the same time and it was as though something here got trapped in between something and it really hurt. I tried to do it again, it didn't happen. A few days later it happened again and it got worse. I went to the doctor who said there's no problem. It started getting worse but he was insisting there was no problem and eventually he decided he would send me to see someone. Meanwhile it was getting near to Christmas, that was Christmas 2004, and I was in that much pain because on the night when I was going to sleep I had to get my head in a position where when I swallowed that thing wasn't trapped, whatever it was. Anyway I went private in the end my husband said "look you're not going to be like this over Christmas". But 22 months on no different. But two months after that I start getting pain coming up here (1A)

I've had the camera down [her throat by ENT] twice and I've told them it's not inside my throat it's here. If I turn my head, extend my neck this way, that quite … often can set it off. Anyway, about two months later I start getting pain going up here and it got worse and worse. And one of the Consultants I saw was the Ear, Nose & Throat dept, Mr Samuel, and I told him I was … I started getting a lot of pain in my ear. So he looked in my ear "oh there's nothing wrong with your ears". Anyway this pain just got worse and worse and quite often it comes up the side of here as well, and I get quite a bit of swelling here. But the pain, when it comes on, it's absolutely terrible. I get pain there and pain in my ear. And it was the last Consultation I had with Mr Samuel, when I was going on about this again, and at this point in time it was swollen here, and he came round the back and started moving my head about and that and he said "you've got jaw problems" and he said "go to your dentist" he said "you need some splints making for the sleeping". Well I went to the dentist and he says "oh we don't do them" and I said "well can you refer me to the dental hospital?" (2A)

It wasn't just a little niggle, it was a pain. And as time's gone on it's got worse and worse and I … when it comes on really bad I'm sitting and holding the side of my face and pressing here, because it does get bad (3A)

Yeah. I saw him privately at the [name] Hospital which he [private ENT Consultant] put the camera down, told me there was nothing in there, and all I got out of him was cut the cigarettes and stop drinking coke and that was me conclusion (3B)

He [ENT NHS consultant] put the camera down again, once again [after previous private consultation] and says it's not in here it's here. And he was quite happy (4A)

[After private consultation] And as I was coming … I told them that my doctor had made … I'd got an appointment for January to see Mr [ENT Consultant NHS], no another gentleman, can't think of his name. He [GMP] says "keep that appointment as a second opinion" (4B)

Yeah. He was the one … I can't think of this chap's [name]… I've seen that many Consultants (4C)

Also in the middle of this [repeated visits to different consultants] my family doctor says because he was … I had to change doctors in the middle of this. The family doctor said "have you had your teeth checked out? You know, it could be coming from your teeth into your jaw". So the doctor referred me to [oral and maxillofacial surgery]. (6A)

Absolutely terrible. I mean I said to him on more than one night, I says "I'm not going mad. I know you're telling me that medically you're saying there's nothing wrong, but there is something wrong". The same with the pain here. People were saying "well, you know, the doctor's said there's nothing wrong with you here". But I knew about the pain I was suffering. (11A)

Mr [NHS ENT Consultant] said to go to the dentist and have a splint made. The dentist says they didn't make them. So I asked if I could be referred to the Dental Hospital. And meanwhile I was at the doctors because I've got a lot going on health-wise at the moment. And I'd mentioned it to the doctor and she says "I'll refer you". (11B)

[what sort of things did you think it might be?] Cancer (12A)

Suffering something and nothing gets done about it. I mean this thing in my neck still nothing's done about that, can't do anything about it. Saying there's nothing there, but I know there's something there. I know there's something there. The painkillers I'm on don't do much (13A)

I mean what with the chronic fatigue syndrome and the fibromyalgia and arthritis. Those three things together some days I feel as though I've got very little energy, I could do very little in the house. I mean my husband, who's a lot older than I am, and he does everything for me. And then … so I've got that pain to start with. And then this other nagging pain going on. And, you know, them saying there's nothing wrong. Oh I'll tell you, I cried and I cried and cried. And I said life wasn't worth living, my husband will tell you that (14A)

But, I mean, many a night I cried and cried and cried in pain (15A)

At a point I sat and thought am I feeling this. And I thought I am feeling … I know it's not in my mind, the pain was so bad. I know it's not in my mind (15B)

Oh yeah, because all these professionals are saying there's nothing wrong. But 22 months down the line I'm no further on, but I still know there's something there, whether it's not something simple, it maybe something that's caused from the thyroid, you know, the cartilage, it may be something to do with the fibromyalgia. Whatever it is, all I wanted to know was what was happening and what was causing it. Not the fact that … I mean, yeah it mustn't be anything serious because if it had been cancer 22 months later I don't think I'd be still in this condition. But the fact that nobody's told me yes you've got such and such. I mean they've told me I've got this chronic fatigue syndrome fibromyalgia. I suffer with this, but I get nothing done for it. Nobody does a thing. I know very little about it but nobody does anything for me for it (16A)

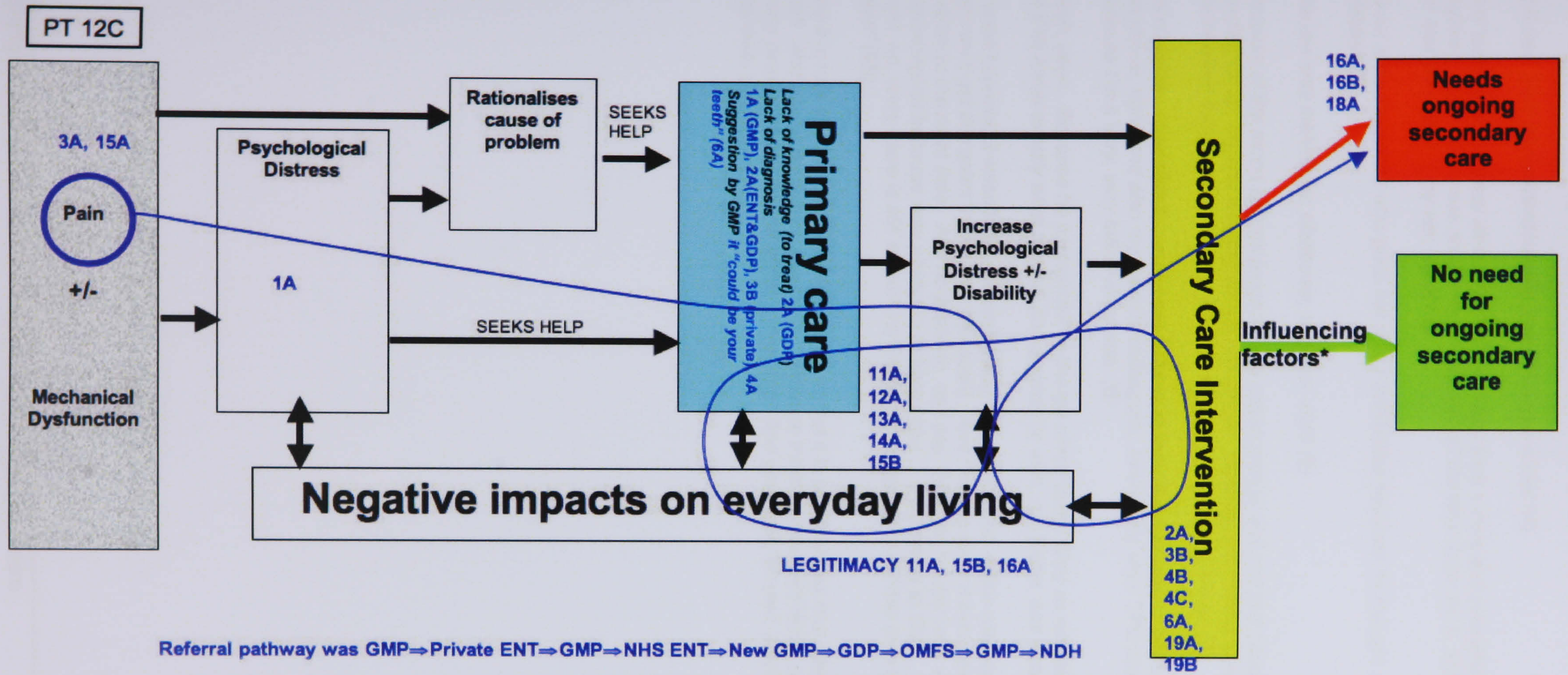
Well it's some comfort to know there is something wrong. Even better if you can be helped with it, right. But, I mean, I've got fibromyalgia and chronic fatigue – get no help from that, yet they tell me what it is, I don't know a lot about it, I don't get help with it. I have to tolerate, I have to put up with it. But the fact of the Temporomandibular problem – yeah I know what that is, and the fact that I've got some help with it is a great relief. And I do think this splint is doing some good. And hopefully it continues, even if I've got to wear it forever and a day. I'd wear it (16B)

It certainly does something because, you know, this has gone on for so long and you're suffering the pain and people saying you know, there's nothing there, there's nothing wrong. And to find out what is wrong and getting some help makes a tremendous difference (18A)

From the first private consultation I was disgusted with that. And Mr [OMFS consultant], who I saw, he just wasn't interested at all. When I … the doctor had mentioned has your teeth been checked properly? I mean I've been going to the dentist for a long while and I'd seen something on the television where they did an x-ray from inside the mouth and you could see all the jaw, the teeth in the jaw and under here, and thought oh maybe when I see [the OMFS consultant] he'll do something like that and then he'll be able to sort my jaw then. And all he said was "if it was something wrong it would have shown up on the scan"….. he asked about who I'd seen and I told him one of the consultants. This is stupid because I'll have all the documentation sent to one. It's stupid seeing all these consultants and he just said there was nothing wrong and that was it (19A)

but I felt it was a waste of mine because early hospital appointment is not easy for me and trekking down to the hospital to have that thrown back at you again that there's nothing wrong. I tried to find out what was wrong, the thyroid biopsy – it was very painful because they don't give you any local anaesthetic or anything. Three times I went in here for my thyroid and it was excruciating (19B)

I mean the reason that I wanted to come on the trial [this interview], I mean I didn't know if it was a group session or what, but I'll tell you the first reason I wanted to come, in case it was a group session, was to see if anyone else had had the problems. But you never know that you might get one out of 500 people that might have a similar problem. And it would be just nice to talk to somebody. And this was one of the first reasons I thought about coming on the trial. And I thought well I've got nothing to lose, because I've found out what the problem is, and I would follow it through as far as I could (20A)



* **Influencing factors include:**

- Reduction in pain – **hasn't had enough reduction in pain yet to no longer require treatment 16B**
- Understanding source of complaint **20A**
- Confidence in clinician, diagnosis and ability to self manage the condition
- Positivity in having reference point – **hasn't got one yet, came looking for one by attending interview 20A**

8.3.12 PT 13C

And then I got this horrendous like jaw ache, you know(1A)

That was the emergency clinic, that's right. They took x-rays and everything and they couldn't really see anything, right. But it was so like from here and all the way down here, my neck, and it went round the ear and then behind my ear, right(1B)

I went to see a dentist who gave me some antibiotics because he thought maybe it might have been an infection (2)

The jaw was making us, obviously, very low, right (6)

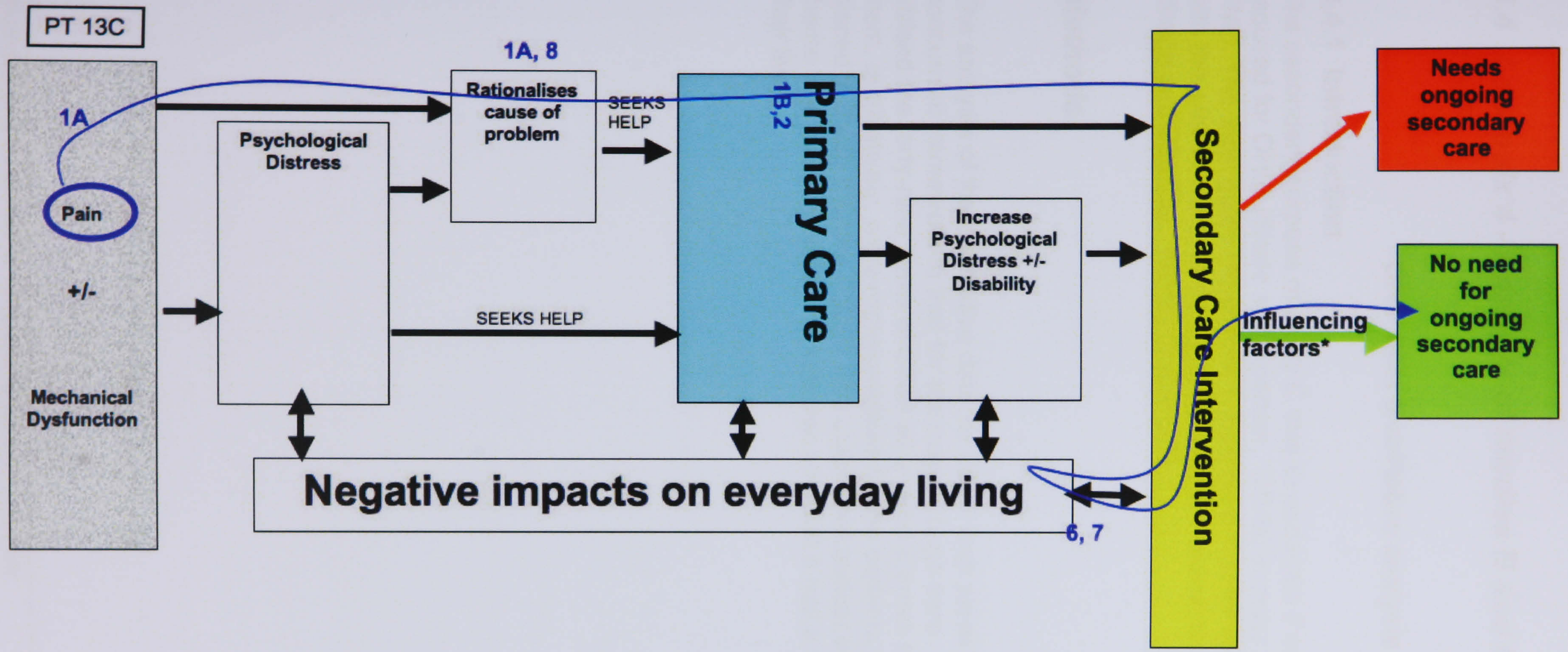
Because of the mood swings [anger]. The mood swings and just that I couldn't cope with my husband winding us up, my son winding me up, you know. Running your home, you know, doing your housewifely things, trying to do a full-time job, you know, and it's a lot (7)

I don't know. I just didn't … well I put it down to that I talk too much. Because obviously I'm always on the phone, right, and also my friends, colleagues, everybody says "[Pts name] do you ever shut up?". Because I'm a very, very talkative person. (8)

Yeah, yeah. Because he [consultant in charge of her case] filled us with confidence and he … like I felt as if he knew exactly what he was doing, what he was, you know, and gives us confidence (9A)

It wasn't cancer, it wasn't this, I wasn't going to have to have major operations, it was just the case of right we'll get this splint in, we'll try this splint. And I had to wear it every day at first. Then we'll reduce it down to the night time. And no problem, as I say, through the day until, as I say, I think it's definitely psychological because now when I'm in here I can … it's starting to like … it's in my mind suddenly says "right, no, sorry there is still something there and I'm going to tell this man that there is still something there" (9B)

And it is nice to know, it's horrible and rotten, but it is nice to know that other people are in the same boat. And you're not alone, you know. Because it's the same with IBS, I suffered from that. And how many people, when I talked about it, had this. And you think "ah well, that's alright". I'm not just the only one, you know (12)



* **Influencing factors include:**

- Reduction in pain **9A**
- Understanding source of complaint **9A, 9B**
- Confidence in clinician, diagnosis and ability to self manage the condition
- Positivity in having reference point **12**

8.4 Appendix 4 - Analysis of studies B and C for new OHIP items

OHIP Item Qualitative analysis

8.4.1 Introduction

The secondary purpose of study C was to ascertain if any new items were required for OHIP (Slade and Spencer, 1994b) in order for it to be used with TMD. The topic guide (Appendix 1, Section 8.1.2) for study C was constructed with this also in mind, ensuring that the seven domains of OHIP were covered (Slade and Spencer, 1994b) (Table 8-1).

Methods

The analysis of the qualitative data for OHIP took place in a separate but concurrent framework to that for the map through care. This framework utilised the forty-nine items of OHIP as a priori themes to investigate which of them, qualitatively, were representative for the patients interviewed. Data was placed in these themes if there was qualitative textual evidence that the theme was relevant to the interviewee and that it had a frequent impact on their lives.

Table 8-1 OHIP 49, as modified for TMD by Moufti (Moufti 2007)

Domain	Item No.	Item
Functional limitation	1	Have you had difficulty chewing any foods because of problems with your teeth, mouth, dentures or jaws?
	2	Have you had trouble pronouncing any words because of problems with your teeth, mouth, dentures or jaws?
	3	Have you noticed a tooth that doesn't look right?
	4	Have you felt that your appearance has been affected because of problems with your teeth, mouth, dentures or jaws?
	5	Have you felt your breath has been stale because of problems with your teeth, mouth, dentures or jaws?
	6	Have you felt your sense of taste has worsened because of problems with your teeth, mouth, dentures or jaws?
	7	Have you had food catching in your teeth or dentures
	8	Have you felt that your digestion has worsened because of problems with your teeth, mouth, dentures or jaws?
	9	Have you felt that your dentures have not been fitting properly?
Physical Pain	10	Have you had painful aching in your mouth?
	11	Have you had a sore jaw?
	12	Have you had headaches because of problems with your teeth, mouth, dentures or jaws?
	13	Have you had sensitive teeth, for example, due to hot or cold foods or drinks?
	14	Have you had toothache?
	15	Have you had painful gums?
	16	Have you found it uncomfortable to eat any foods because of problems with your teeth, mouth, dentures or jaws?
	17	Have you had sore spots in your mouth?
	18	Have you had uncomfortable dentures?
Psychological discomfort	19	Have you been worried by dental problems?
	20	Have you been self-conscious because of teeth, mouth, dentures or jaws?
	21	Have you found dental problems made you miserable?
	22	Have you felt uncomfortable about the appearance of your teeth, mouth, dentures or jaws?
	23	Have you felt tense because of problems with your teeth, mouth, dentures or jaws?
Physical disability	24	Has your speech been unclear because of problems with your teeth, mouth, dentures or jaws?
	25	Have people misunderstood some of your words because of problems with your teeth, mouth, dentures or jaws?
	26	Have you felt that there has been less flavour in your food because of problems with your teeth, mouth, dentures or jaws?
	27	Have you been unable to brush your teeth properly because of problems with your teeth, mouth, dentures or jaws?
	28	Have you had to avoid eating some foods because of problems with your teeth, mouth, dentures or jaws?
	29	Has your diet been unsatisfactory because of problems with your teeth, mouth, dentures or jaws?
	30	Have you been unable to eat with your dentures because of problems with them?
	31	Have you avoided smiling because of problems with your teeth, mouth, dentures or jaws?

Domain	Item No.	Item
	32	Have you had to interrupt meals because of problems with your teeth, mouth, dentures or jaws?
Psychological disability	33	Has your sleep been interrupted because of problems with your teeth, mouth, dentures or jaws?
	34	Have you been upset because of problems with your teeth, mouth, dentures or jaws?
	35	Have you found it difficult to relax because of problems with your teeth, mouth, dentures or jaws?
	36	Have you felt depressed because of problems with your teeth, mouth, dentures or jaws?
	37	Has your concentration been affected by problems with your teeth, mouth, dentures or jaws?
	38	Have you been embarrassed because of problems with your teeth, mouth, dentures or jaws?
Social disability	39	Have you avoided going out because of problems with your teeth, mouth, dentures or jaws?
	40	Have you been less tolerant of your spouse or family because of problems with your teeth, mouth, dentures or jaws?
	41	Have you had trouble getting on with other people because of problems with your teeth, mouth, dentures or jaws?
	42	Have you been a bit irritable with other people because of problems with your teeth, mouth, dentures or jaws?
	43	Have you had difficulty doing your usual jobs because of problems with your teeth, mouth, dentures or jaws?
Handicap	44	Have you felt that your general health has worsened because of problems with your teeth, mouth, dentures or jaws?
	45	Have you suffered any financial loss because of problems with your teeth, mouth, dentures or jaws?
	46	Have you been unable to enjoy other peoples company as much because of problems with your teeth, mouth, dentures or jaws?
	47	Have you felt that life in general was less satisfying because of problems with your teeth, mouth, dentures or jaws?
	48	Have you been totally unable to function because of problems with your teeth mouth or dentures?
	49	Have you been unable to work to your full capacity because of problems with your teeth, mouth, dentures or jaws?

Whilst inputting data into the a priori themes any recurrent differences in the patients' phraseology were noted to allow for modification of the items in the eventual outcome measure. Any recurrent emergent themes that affected the patients' quality of life but which were not already covered were added to the framework and the patients' terminology was carefully considered to allow new items to be formulated from these recurrent emergent themes.

The following sections will first present the qualitative data and discussion and will then compare the qualitative findings to the data from the quantitative study by Moufti (Moufti, 2007), specifically highlighting potential new items and discussing any similarities or differences.

8.4.2 Results

The forty-nine a priori items were supported by varying degrees of data; some had abundant text references and some had none at all. It is simplest to first discuss those redundant items that had no qualitative data supporting them. Table 8-2 outlines these by domain.

Table 8-2 – OHIP items unsupported by Qualitative data

Domain	Item No.	Summary of item
Functional limitation	3	Noticed a tooth that doesn't look right
	5	Breath has been stale
	6	Sense of taste has worsened
	7	Food catching in your teeth
	8	Felt that your digestion has worsened
	9	Dentures have not been fitting properly
Physical Pain	15	Had painful gums
	18	Had uncomfortable dentures
Psychological discomfort	23	Felt tense because of problems
Physical disability	26	Less flavour in your food
	27	Unable to brush your teeth properly
	30	Unable to eat with your dentures
	31	Avoided smiling
	32	Interrupt meals

Just because an item is unsupported by the qualitative data does not necessarily mean it would not score if it were administered in a questionnaire format. It is, however, likely that these items are of less importance to TMD sufferers and not specific to their complaint, as they have not been raised as specific complaints during 29 interviews. Bearing in mind the previously reported sufferer's experience it is unsurprising to see that the majority of the redundant items lie in the functional and physical disability domains and that the handicap, psychological and social disability domains had no redundant items. This reinforces the importance of the psychosocial effects of TMD, which may, as has been shown, perpetuate and to ultimately handicap the patient.

Qualitative data by its nature is exploratory and explanatory rather than attempting to quantify findings, however, in order to demonstrate the degree of relative importance of those items that had data recorded Table 8-3 gives the number of patients (n=29) that gave data supporting the a priori themes.

This content analysis is not for statistical purposes but for illustration and to give an indication of the item's relevance to the interviewees.

Table 8-3 OHIP Items with qualitative data

Domain	Item No.	Summary of item	Frequency of Qualitative reports (n=29)
Functional limitation	1	Chewing any foods	20
	2	Pronouncing any words	1
	4	Appearance has been affected	3
Physical Pain	10	Painful aching in your mouth	21
	11	Had a sore jaw	21
	12	Had headaches	13
	13	Had sensitive teeth	1
	14	Had toothache	10
	16	Uncomfortable to eat any foods	19
	17	Sore spots in your mouth	1
Psychological discomfort	19	Worried by dental problems	20
	20	Self-conscious	4
	21	Dental problems made you miserable	9
	22	Uncomfortable about the appearance	1
Physical disability	24	Has your speech been unclear	3
	25	People misunderstood some of your words	1
	28	Had to avoid eating some foods	15
	29	Diet been unsatisfactory	1
Psychological disability	33	Sleep been interrupted	17
	34	Been upset	6
	35	Difficult to relax	4
	36	Felt depressed	11
	37	Concentration been affected	2
	38	Been embarrassed	1
Social disability	39	Avoided going out	2
	40	Less tolerant of your spouse or family	6
	41	Trouble getting on with other people	2
	42	Been a bit irritable with other people	8
	43	Difficulty doing your usual jobs	8
Handicap	44	Your general health has worsened	2
	45	Suffered any financial loss	2
	46	Unable to enjoy other peoples company as much	4
	47	Life in general less satisfying	5
	48	Totally unable to function	3
	49	Unable to work to your full capacity	8

As can be seen from Table 8-3, TMD would appear to affect all domains of oral-health related quality of life; it particularly affects most aspects of Handicap, Social and Psychological Disability. It affected these three domains in an individualistic fashion as the quotes below illustrate.

> *"If I had to concentrate on anything my concentration span [pause] like I was sat down with my little boy on the floor, I couldn't concentrate on doing like putting, helping him do a jigsaw, anything like that was just [pause] too much for me, yeah." (Pt 9B) [Item 37]*

> *"I wasn't sleeping at night properly and therefore I was tired when I went to work and then I was probably getting more stressed and my tolerance level was probably lower" (Pt 6C) [Items 33,41,42]*

> *"I don't know what went wrong at work, but I really went downhill for some reason, and then I went back to the doctor and he sent us up here and they put us on morphine. So I did have a bit of time off work" (Pt 10B) [Items 43 & 49]*

One of the major impacts of TMD occurs both as a (physical) disability and as a functional limitation, in chewing and eating (Items 1 and 16). This impact had two major causes, hard foodstuffs and limited opening. Chewing harder foodstuffs was difficult with, and without, limited opening due to the pain that was caused by: a) the bite force required to masticate; and b) the amount of mastication that had to occur.

> *"I mean certain things I always liked and I avoid because that made it worse. Like I love crusty buns and I just avoid anything where I've got to chew too much, you know. Because I keep thinking there's no point in putting yourself in pain, you know. So some of the things I have cut out to save like the pain, you know" (Pt 7C) [Items 1 & 16]*

> *"I used to have to just pick, you know, pick certain foods that I didn't need to chew...it just wasn't worth the hassle, you know, it was an easy option, not to eat meat, you know" (Pt 1B) [Item 1 & 16]*

The limited opening patients complained about could be due to: a) physical limitation, for example a unreduced dislocated disc; or b) the pain the patient experienced in their muscles of mastication on opening wider. In either case it affected chewing and eating giving impacts in items one and sixteen.

"I couldn't … the volume of food I couldn't pile up my fork and stuff it in so I was eating slower and I think I stopped eating as much really just because I was eating slower. And then I stopped eating certain foods. So I'd maybe just eat pasta rather than say if I had a roast dinner then roast potatoes would have to be mashed down and things like that" (Pt 5C) [Item 1 & 16]

"Different kinds of food. If I was eating toffee, well I couldn't eat toffee. Couldn't eat Hamburger because I couldn't get my mouth open that wide. Like hard food, like chewy food" (Pt 17C) [Item 1]

The relative importance of the Physical Pain and Psychological Discomfort domains in comparison to the other domains (Table 8-3) is unsurprising given the experiences reported during the patients' journey through care, especially in relation to the worry their complaint caused. Physical pain was the one domain where the terminology used in the OHIP question may have been inaccurate for the individual's experience, particularly in items ten and eleven. Items ten and eleven, due to OHIP's oral health basis, relate the pain experienced to the "mouth" (10) and "jaw" (11). As is demonstrated by the quotes below and earlier sections of the thesis (Sections 5.2.2 and 5.3.2), the pain individuals experience can radiate outside of the mouth and can be both difficult to relate to specific structures and difficult to quantify. It may therefore be pertinent to broaden one of items eleven and ten to include face and ear region.

> *"It was really hard to pinpoint. It was [pause] felt like it was all over one … it was just on my left side, not both, and it just felt like it was all over. Even in my ear I could feel some pain and no definite origin of it" (Pt 5C) [Items 10,11,17]*
>
> *"I found that I had a swelling on the side of the face. And it was more or less like earache as well. So it would sort of go to the ear and travel up to the side of the … to the eye and my head" (Pt 8B) [Items 10 & 11]*

The broadening of item(s) ten or eleven might then allow the patients to score these items when they are uncertain of the source of their pain but it might also make the item too generic, allowing impacts for other types of facial pain. If changes were made, the statement(s) would have to undergo validity testing, particularly face and construct validity.

Emergent themes

In terms of emergent themes from the qualitative data and therefore possible new items to include in OHIP there were, as expected, very few and they occurred in only three domains, Functional limitation, Physical pain and Physical disability. The common emergent themes that were not accounted for specifically in OHIP were:

- Difficulties with mouth opening. Domains - Functional limitation, (Physical disability)
- Arrangement of teeth (in relation to a "comfortable bite"). Domain - Functional limitation
- Painful speech. Domain - Physical Pain

Difficulties with mouth opening were expressed in terms of lack of opening (example: Pt 8C below) and less commonly as an inability to close fully (example: Pt 16C below); both were described in terms of a functional limitation that could cause psychological discomfort and social disability. The psychological and social disability expressed would, however, be covered by items already within those domains at present.

> *"I do get quite distressed when I have to have [dental] impressions taken or when people say "oh open it wider" and I say "I simply can't". Some people think I'm actually being, you know, obstructive. I'm not, I simply cannot open my mouth very wide, and if I do it will hurt terribly and then click and sometimes lock. And that's quite frightening" (Pt 8C)*

> *"My jaw locked open to the point where I couldn't close it and ended up going through a bizarre and unpleasant experience" (Pt 16C)*

The functional limitation of a decrease in mouth opening was the strongest new emergent theme from the qualitative data in relation to OHIP. It would seemingly be a useful item to record the problems some TMD patients experience, particularly those with myofascial pain and disc displacement.

Individuals also mentioned the arrangement of their teeth as a functional limitation.

> *"Probably off centre [the jaw]. It just, my mouth just didn't feel right having lost it, because it's a big tooth that I've lost [removed by dentist trying to stop the pain]...I just felt that with the removal of the tooth I'd made it worse because it was as though my jaw was … it felt as though it wasn't in alignment when I ate" (Pt 3C)*

The functional limitation of a feeling of misalignment, however, was reported by a few people through the data and seemed to have only a minor impact. For some of these individuals, however, it was immensely preoccupying. As alignment has a low prevalence and impact in the wider group, there are two issues to discuss. The first is that it is so unique that it may well merit inclusion as a new item for further testing in the prototype outcome measure. The second is that it may have been brought about by specific treatment the individuals in question had received, for example an occlusal equilibration. *"The feeling that my mouth is big enough to take my tongue and I can speak properly, and my teeth to be re-aligned so that fit right. Just think they don't fit right"* (Pt 1C). It should, however, be noted as an exacerbating factor for TMD patients at present and further investigation will be required to determine whether or not it is included in the prototype measure.

The final emergent theme was one relating to physical pain; patients often recounted their TMD causing a great deal of pain when speaking, especially if for long periods of time.

> *"I had it during the day as well because I worked as a Receptionist and I found that if I'd been talking a long time, speaking a long time on the telephone it was really painful by the end of the evening, it was really sore. And I couldn't stand anyone else to touch the side of my face" (Pt 8B)*

> *"Just, as I say, when I spoke. Just speaking seemed to make everything sore and achy" (Pt 3C)*

This emergent theme of pain during speech is potentially useful as a new item as it is not examined elsewhere in OHIP. It is also likely to have a high impact especially if the individual's occupation involves large amounts of conversation.

The emergent themes and their relative frequencies are shown in Table 8-4.

Table 8-4 - Emergent themes and their relative frequencies

Domain	Item No.	Summary of new additional item	Frequency of Qualitative report (n=29)
Functional limitation	Add	Difficulties in opening and closing your mouth	11
	Add	*Alignment of teeth*	4
Physical Pain	Add	Felt speech was painful	7
Physical disability	Add	*Unable to eat*	2

Italics indicate themes unsuited to become items
The full wording is given in Table 8-6

There was a recurrent complaint throughout the data set about clicking on opening, which is not examined specifically within OHIP. The complaint, however seemed to have few impacts on quality of life that were not already captured by the standard OHIP items in the general cohort. It seemed to cause the psychological discomforts of worry and self-consciousness to only one individual.

> *"Yeah, very conscious of it, certainly. It would make people turn round and say what on earth is that, because it was just so loud. And be on the left side. It was like a bullet going off" (Pt 17B)*

The most appropriate use of this individual's perspective is to ensure in the final selection of items for the outcome measure that these areas are covered. Specifically, this means including items 19 and 20 in any outcome measure, which the quantitative data would corroborate.

Comparison of qualitative and quantitative data on items

Table 8-5 gives the frequency of occurrence in the qualitative data, including those that had no data, compared with the quantitative results of each item from the study by Moufti (Moufti, 2007). It also compares the a priori qualitative selection of items against the quantitative selection. Both selections are based around trying to preserve the domain structure of OHIP (Allen and Locker, 2002; Slade, 1997), which means that its original construct, Locker's model of Oral health (Locker, 1988), stays intact. The selection based on the case control study was dependent not on frequency but on differences between cases and controls according to pre-determined limits.

Table 8-5 Qualitative and quantitative frequencies of each item

Domain	Item No.	Summary of item	Qualitative report (n=29)	Difference in Mean	Difference in Median	Difference in % FOVO	Difference in Item-Impact	Quantitative Inclusion	Qualitative Inclusion
Functional limitation	1	Chewing any foods	20	**2.12**	**2**	45%	***120.4***	X	X
	2	Pronouncing any words	1	0.71	0	7%	7.5		
	3	Noticed a tooth that doesn't look right	0	0.03	0	1%	1.0		
	4	Appearance has been affected	3	0.50	1	9%	14.9		
	5	Breath has been stale	0	0.42	1	13%	13.8		
	6	Sense of taste has worsened	0	0.37	0	7%	4.7		
	7	Food catching in your teeth	0	0.19	0	17%	32.5		
	8	Felt that your digestion has worsened	0	0.40	0	5%	2.6		
	9	Dentures have not been fitting properly	0	0.08	0	3%	0.7		
	Add	Had difficulties in opening and closing your mouth	11	n/a	n/a	n/a	n/a		X
Physical Pain	10	Painful aching in your mouth	21	**1.90**	**3**	52%	133.9	X	X
	11	Had a sore jaw	21	**2.70**	**3**	67%	***205.2***	X	X
	12	Had headaches	13	**1.78**	**2**	41%	87.1	X	X

Domain	Item No.	Summary of item	Qualitative report (n=29)	Difference in Mean	Difference in Median	Difference in % FOVO	Difference in Item-Impact	Quantitative Inclusion	Qualitative Inclusion
	13	Had sensitive teeth	1	0.47	1	13%	27.7		
	14	Had toothache	10	0.56	1	10%	15.8		
	15	Had painful gums	0	0.69	1	18%	26.1		
	16	Uncomfortable to eat any foods	19	**1.87**	**2**	44%	113.7	X	X
	17	Sore spots in your mouth	1	0.58	1	16%	21.7		
	18	Had uncomfortable dentures	0	0.09	0	2%	0.5		
	Add	Felt speech was painful because of problems with your jaw	7	n/a	n/a	n/a	n/a		X
Psychological discomfort	19	Worried by dental problems	20	**2.08**	**3**	51%	***132.6***	X	X
	20	Self-conscious	4	**1.00**	**2**	23%	43.0	X	X
	21	Dental problems made you miserable	9	**1.65**	**2**	36%	75.7	X	X
	22	Uncomfortable about the appearance	1	0.56	0	11%	13.0		
	23	Felt tense because of problems	0	**1.72**	**2**	33%	65.7	X	
Physical disability	24	Has your speech been unclear	3	0.54	0	5%	4.6		
	25	People misunderstood some of your words	1	0.38	0	5%	2.3		
	26	Less flavour in your food	0	0.27	0	3%	1.2		
	27	Unable to brush your teeth properly	0	0.99	1	19%	25.4		
	28	Had to avoid eating some foods	15	**1.93**	**2**	39%	***93.0***	X	X
	29	Diet been unsatisfactory	1	0.73	0	9%	7.6		
	30	Unable to eat with your dentures	0	0.12	0	4%	0.7		
	31	Avoided smiling	0	0.44	0	12%	10.3		

Domain	Item No.	Summary of item	Qualitative report (n=29)	Difference in Mean	Difference in Median	Difference in % FOVO	Difference in Item-Impact	Quantitative Inclusion	Qualitative Inclusion
	32	Interrupt meals	0	**1.29**	**1**	24%	35.2	X	
Psychological disability	33	Sleep been interrupted	17	**1.52**	**2**	33%	***59.0***	X	X
	34	Been upset	6	**1.46**	**2**	24%	44.6	X	
	35	Difficult to relax	4	**1.57**	**2**	29%	54.7	X	
	36	Felt depressed	11	**1.10**	**1**	15%	19.5	X	X
	37	Concentration been affected	2	**1.37**	**2**	21%	33.7	X	
	38	Been embarrassed	1	0.66	0.5	11%	12.1		
Social disability	39	Avoided going out	2	0.39	0	5%	2.7		
	40	Less tolerant of your spouse or family	6	0.90	0	12%	13.5		
	41	Trouble getting on with other people	2	0.39	0	4%	2.0		
	42	Been a bit irritable with other people	8	0.99	1	12%	***14.5***	X	X
	43	Difficulty doing your usual jobs	8	0.61	0	11%	8.8		X
Handicap	44	Your general health has worsened	2	0.74	0	10%	8.6		
	45	Suffered any financial loss	2	0.09	0	1%	0.2		
	46	Unable to enjoy other peoples company as much	4	0.60	0	7%	5.9		
	47	Life in general less satisfying	5	0.94	1	11%	***12.3***	X	
	48	Totally unable to function	3	0.34	0	6%	2.5		
	49	Unable to work to your full capacity	8	0.68	0	10%	7.9		X

Highest difference in item-impact in each domain in ***bold italic***
Clinically meaningful (one unit) difference between patient and controls' mean and median in **bold**

- Indicates difference between quantitative selection and qualitative selection
- Indicates difference between qualitative selection and quantitative selection
- Indicates additional item

There are eight items that the qualitative and quantitative data disagree on. As a general rule the quantitative statistical selection should take precedence

over the qualitative except in cases where the qualitative data highlights the importance of a new item. So in the cases of items 23, 32, 34, 35, 37 and 47 these items should, due to their statistical significance continue to be selected for the prototype outcome measure, subject to sensitivity of change testing. In terms of those items in the Psychological disability domain of OHIP (32, 34, 35 & 37) the qualitative data would support the need for several items to thoroughly ascertain their relevance to the TMD patient.

Items 43 and 49 are related in that they seek to measure the impact of the condition on the individual's day-to-day functioning and work. This has been shown throughout the qualitative data to be a very important gauge of the severity of the individual's TMD. A decrease in this or a cessation of TMD's interference in these activities would, from the qualitative data, seemingly be an important indicator of recovery. I would therefore recommend these two items for inclusion into the outcome measure despite their statistically low impact. Alternatively a single new question could be developed on this theme, which has greater resonance with TMD sufferers.

The Social Disability and Handicap domains represent severe impacts and understandably occur at a low prevalence. This means that when comparing TMD sufferers with controls there were "floor effects" meaning some important items were potentially excluded on the basis of statistical analysis. The qualitative analysis, however, has helped us to identify the most important items to the sufferer in each of these domains.

Item 20 has been included due to its high statistical impact and I have suggested that qualitatively it should also be included. This is due to the need for a question to ascertain the impact of loud clicks on the individual.

8.4.3 Summary

The preliminary recommendations for items to be included in the outcome measure on the basis of this analysis are detailed in Table 8-6.

Table 8-6 Preliminary recommendations for items to be included in outcome measure

Domain	Item No.	Item
Functional limitation	1	Have you had difficulty chewing any foods because of problems with your teeth, mouth, dentures or jaws?
	Add	Have you had difficulties in opening and closing your mouth?
Physical Pain	10	Have you had painful aching in your mouth?
	11	Have you had a sore jaw?
	12	Have you had headaches because of problems with your teeth, mouth, dentures or jaws?
	16	Have you found it uncomfortable to eat any foods because of problems with your teeth, mouth, dentures or jaws?
	Add	Have you felt speech was painful because of problems with your teeth, mouth, dentures or jaws?
Psychological discomfort	19	Have you been worried by dental problems
	20	Have you been self-conscious because of problems with your teeth, mouth, dentures or jaws?
	21	Have you found dental problems made you miserable
	23	Have you felt tense because of problems because of problems with your teeth, mouth, dentures or jaws?
Physical disability	28	Have you had to avoid eating some foods because of problems with your teeth, mouth, dentures or jaws?
	32	Have you had to interrupt meals because of problems with your teeth, mouth, dentures or jaws?
Psychological disability	33	Has your sleep been interrupted because of problems with your teeth, mouth, dentures or jaws?
	34	Have you been upset because of problems with your teeth, mouth, dentures or jaws?
	35	Have you found it difficult to relax because of problems with your teeth, mouth, dentures or jaws?
	36	Have you felt depressed because of problems with your teeth, mouth, dentures or jaws?
	37	Has your concentration been affected because of problems with your teeth, mouth, dentures or jaws?
Social disability	42	Have you been a bit irritable with other people because of problems with your teeth, mouth, dentures or jaws?
	43	Have you had difficulty doing your usual jobs because of problems with your teeth, mouth, dentures or jaws?

Domain	Item No.	Item
Handicap	47	Have you felt that life in general was less satisfying because of problems with your teeth, mouth, dentures or jaws?
	49	Have you been unable to work to your full capacity because of problems with your teeth, mouth, dentures or jaws?

Table 8-6 is by no means the final constitution of the measure. The research group need to discuss both the qualitative and quantitative results and agree a format for the measure. Any new (additional) items included will need face and content validity testing. This validity testing needs to occur prior to undertaking the final validation of the outcome measure and will probably take the form of a number of small focus groups involving individuals suffering from TMD and professionals who mange TMD.

8.5 Appendix 5 - Peer-reviewed publication and abstracts from scientific presentations

8.5.1 Peer reviewed publication

RESEARCH

IN BRIEF

- Readers will understand the nature of primary care difficulties in the management of temporomandibular disorders (TMD).
- Readers will understand the basis of management of TMD and the biases it is liable to.
- Readers will be aware of the potential for mismanagement of TMD due to the lack of good quality evidence.

'Management is a black art' – professional ideologies with respect to temporomandibular disorders

J. Durham,[1] C. Exley,[2] R. Wassell[3] and J. G. Steele[4]

Objective To gain a deeper understanding of the range of influences on the full range of dental professionals who provide treatment for temporomandibular disorders (TMD).

Design Qualitative semi-structured interviews.

Setting Primary and secondary care in the North and South of the United Kingdom.

Sample and method A criterion-based purposive sample was taken of dental practitioners, comprising primary and secondary care practitioners. In-depth interviews were conducted and data collection and analysis occurred concurrently until data saturation was achieved.

Data and discussion There was a reported lack of adequate remuneration for provision of treatment for TMD within primary care. This alongside the primary care practitioners' reported uncertainty in diagnosis of TMD appeared to lead to a propensity for referral to secondary care. Practitioners recognised a poor and scanty evidence base on which to base their care, and this allowed for idiosyncratic practice. Often the outcome measure for treatment was a subjective questioning of the patient focussing mainly on relief of pain.

Conclusion There is a need for better quality evidence on which to base TMD treatment, more continuing professional development and improvement in contracting arrangements to enable primary practitioners to feel confident in managing TMD.

INTRODUCTION

There is no 'gold standard' approach to treating temporomandibular disorders (TMD) and treatment strategies vary from lifestyle changes, physiotherapy and simple pain relief, through to the provision of specially made splints, the use of specific medications, adjustments to the occlusion, complementary therapies and occasionally even surgery. Often the approach to treatment seems to include many of these approaches in a seemingly random order with no underlying strategy. There is some reasonable evidence for the efficacy of different treatments, but often this is confusing and difficult to quantify. There has been an attempt to ascertain practitioners' attitude towards TMD utilising quantitative techniques. Tegelberg *et al.*[1] examined clinicians' attitudes towards TMD in adolescents and two separate research teams[2,3] have also examined attitudes towards adults with TMD. However, given the likely complexity of the influences, quantitative studies based solely on researchers' perceptions of what dentists think, do not allow us to fully understand what is going on. This study has used a qualitative approach to gain a deeper understanding of the attitudes and experiences of a range of dental professionals who provide clinical care to people with TMD. If we are ever to achieve a rational, consistent and evidence-based approach to managing TMD it is important that we know and understand where we are starting from.

SAMPLE

A criterion-based purposive sample was taken of dental practitioners comprising primary and secondary care dental practitioners. These were taken from the North and South of the United Kingdom, as we hypothesised that there might be differences in practice as a result of socio-geographical influences. Where possible we interviewed individuals distant from academic institutions as well as those from within, to ensure a breadth of views. Table 1 shows the identification method, the inclusion criteria and numbers of each practitioner type included in the sample. From experience[4] it was felt that given the range of professionals involved, approximately twenty interviews would be necessary for saturation to be achieved. Saturation is deemed to have occurred when no new ideas or themes can be identified from the data; in this study this was achieved after eighteen interviews.

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Table 1 Outline of selection criteria for sample

Primary or secondary care	Type of practitioner	Identification and selection criteria	North	South	Total
Primary	New GDP (NGDP)	GDPs less than five years qualified at the time of interview and with no further accredited postgraduate qualification were identified from the GDC register	1	1	2
	Experienced GDP (EGDP)	GDPs greater than five years qualified with or without further qualifications were identified from the GDC register	1	1	2
	Special interest GDP (SIGDP)	GDPs were identified from the membership of the British Society for Occlusal Studies	2	0	2
Total					6
Secondary	Oral medicine (OM)	Consultants in oral medicine were identified from the British Society for Oral Medicine's register	1	1	2
	Oral and maxillofacial surgery (OMFS)	NHS and academic consultants were identified from the British Association of Oral and Maxillofacial Surgery	5 (2 academic, 3 NHS)	2 (1 academic, 1 NHS)	7
	Restorative dentistry (RD)	NHS and academic consultants were identified from the Association of Consultants and Specialists in Restorative Dentistry's register	2	1	3
Total					12
Cumulative total					18

METHOD

Once the sample was identified, dental practitioners were invited to take part in an in-depth interview by a standard letter with accompanying reply and consent form which was posted to their listed address on the appropriate register. If the offer was declined, the next individual that fitted the criteria alphabetically was contacted. The topic guide was not given to any participant prior to their interview.

Semi-structured interviews were used in this study. This method allows for certain key areas to be explored through the use of open-ended questions, whilst at the same time being flexible enough to allow for the exploration of new topics not anticipated at the outset of the study. As interviews progressed, the topic guide evolved according to data gathered. This was an inductive piece of research, with data collection and analysis occurring concurrently. Earlier interviews and their subsequent analysis informed later ones, thus allowing for a detailed exploration of all emergent themes.

The semi-structured in-depth interviews took place in a setting of the interviewees' choice, and at a convenient time for them. All distractions were minimised for an hour, although most interviews took between twenty-five to thirty minutes. All the interviews were undertaken by the same interviewer (JD), after appropriate extensive training. The interviews were digitally recorded and professionally transcribed verbatim. Once transcribed and checked by the interviewer the recordings were destroyed. Two of the authors (JD and CE) reviewed the data and coded it appropriately utilising a framework[5] to help organise the data.

Ethical approval was granted from the Eastern Multi-centre Research Ethics Committee and a grant obtained from the Newcastle Healthcare Charity to afford the General Dental Practitioners (GDPs) reimbursement for their time at the British Dental Association guild rate (£74/hour), and to cover travel and transcription costs.

DATA AND DISCUSSION

As is customary with qualitative research, the data are presented with the discussion to allow development of theory alongside the data.

Three major themes emerged from the data, these related to:

1. Practitioners' perceptions of TMD
2. Practitioners' rationale for interventions used
3. Practitioners' measure of clinical outcome.

Sub-themes developed within each theme, but for the basis of this paper we will discuss, in largely generic terms, each of the three major themes. Quotations will be used to support the developing theory and these are representative of the recurring themes. The reference in parenthesis after each quotation contains the speciality of the practitioner (see Table 1) and a numeric reference to their study number. The sampling included practitioners from the North and South of England, but in terms of the general perceptions no discernable recurrent differences were noted.

Practitioners' perceptions of TMD

When discussing TMD, practitioners tended to view it as an entity in its own right, rather than as a group of sub-classifications. Their perceptions of TMD fell into two broad areas: the perceived aetiology of the condition and their perceptions of the patient. There was widespread variation of opinion on the aetiology of TMD. The only agreement was related to a pivotal role of bruxism and stress in propagating or causing TMD. In addition to these, behaviours such as *'telephone holding in strange ways'* (OMFS 3) and *'sleeping position'* (SIGDP 4) were amongst some of the many purported causes given. This variation seemed to have a concomitant effect on the explanations practitioners were able to give patients for their condition, which again varied widely, as is illustrated below.

'I think it can be quite a distressing condition but in turn I think distress can actually exacerbate or somebody would say, cause the condition... So you get into this vicious circle of what causes what' (OMFS 3).

'...I think it's quite easy to explain a mechanical problem of

disc displacement to a patient if you take your time over it and you would handle it carefully... But the bit that gets difficult is why the problem has arisen because I don't think we know the answers to that. And that's when it gets difficult. So I normally end up telling people what I think that the theories are' (RD 8).

This ambiguity in the aetiology of the condition did not lead to a negative opinion of the patient. In contrast, practitioners empathised with the patient but did view the condition negatively; they felt it was difficult to treat, and in primary care there was an issue with the time taken counselling the patient, time that was ill recompensed. The incumbent fee-per-item system operational at the time had previously been shown not to reward complex or time intensive treatment.[6,7] This is also supported by the primary care practitioners' assertions in this study.

'No I think that they, occasionally you open a large can and sometimes it takes quite a long time to talk through' (EGDP 10).

'I think the treatment of TMD is a very difficult subject to actually approach and unless you get a specialist who specifically likes the treatment of TMD problems, you tend not to get very far anyway' (EGDP 13).

Practitioners' rationale for interventions used

In terms of management of TMD, there was generalised agreement on the need for an initial conservative approach, the constitution of which varied but tended to include some or all of the following: diet/habit modification, physiotherapy, appliance therapy and non-steroidal anti-inflammatory drugs. The primary care practitioners expressed a fear of making a misdiagnosis of TMD and reported a low threshold for referring the patient on to secondary care as a safety net to rule this out. It is likely that this is due in some part to the uncertainty of the aetiology, or their level of education with respect to TMD, an issue which both primary and secondary care practitioners acknowledged. The lack of education described by primary care practitioners may be due to a lack of good quality evidence[6-10] upon which to base practice. This lack of evidence-based practice has led primary care practitioners indirectly to report that they utilise the 'rule out the worse case scenario'[11] approach, referring possible TMD patients to hospital as a safety net. This approach is a heuristic, 'a rule of thumb'. Heuristics are always liable to bias and more so in conditions of uncertainty.[12] In the case of the primary care practitioners, they tended, indirectly, to report a regret bias.[11] In other words, they over-estimate the probability of a diagnosis with a severe outcome due to the problems that might result if an important diagnosis were missed.

'I'm always terrified that I try to do something and really they should be seen by doctors and have their symptoms investigated elsewhere' (SIGDP 4).

'...I might decide that maybe it's the best that they're seen by someone who knows what they're doing rather than someone who's just trying to guess' (NGDP 14).

There was a general reported reluctance in primary care to embark on more complex treatments on the NHS. This appeared to be due to the potential for financial difficulties under the fee-per-item system in place during this study, although this may also be attributed to their uncertainty and a tendency towards dental orthodoxy.[11] Primary care practitioners expressed dissatisfaction with the need to apply for approval for a splint, hard or soft, and the lack of remuneration for the time TMD patients require.

'It's the difficulty with having to write for approval... money comes down to it at the end of the day in General Practice and people need to know what they're taking on [the cost of a lower soft splint] *...I can't understand why the GDS doesn't have a simple code for making a splint'* (EGDP 10).

'...A hard splint now, it's an item you can't get done on the NHS. There will be a fee for it but you can't get a lab who will make you one for a reasonable price. So you're stuck with, you generally have to offer it as a private thing because the lab fee would be more than the fee would be from the NHS.' (SIGDP 17).

Nevertheless, it should be emphasised that suitably trained general practitioners can be very successful at managing TMD,[13] but without adequate remuneration it is questionable that their enthusiasm to continue managing TMD can be maintained.

Secondary care practitioners tended to convey the opinion that primary care could and should be doing more of the initial management of TMD. At present, this apparent discrepancy between primary and secondary care regarding the ownership of initial management of TMD may result in a patient not receiving appropriate care. In a sense, it seems that none of the groups are particularly comfortable taking responsibility for the care of TMD patients. Well targeted continuing professional development courses covering TMD may help some primary care practitioners by allowing them to initially manage TMD with confidence.

'I think that initially the, you know, patients who present to the general dental practitioner with some complicated stress overload, TMJ syndrome, should and could be diagnosed and treated within primary care.' (OMFS 6).

'I think all the sort of baseline treatment that we do here and the diagnostic process is not specialist treatment. I think all that could happen in primary care.' (RD 8).

When secondary care practitioners were asked about their rationales for treatment, they all had experience to call upon which appeared to compensate for the uncertainty caused by the lack of evidence: *'...and consequently* [I] *kind of learni on the job'* (OMFS 6), *'...management* [of TMD] *is a black art'* (RD 2). This experience-based practice was often idiosyncratic, and therefore it is likely that patients' experiences of care and treatment will vary significantly between different professionals. Due to the large variation in management provided between clinicians, it is not feasible to describe the wide variety of treatment protocols for individual diagnoses of the various sub-classifications of TMDs. However, there were general themes of treatment provided that appeared consistent with the type of training the specialist would have received. For example, oral medicine specialists tended to utilise pharmacological interventions, restorative dentists had a

tendency to concentrate on the occlusion and splints and the oral and maxillofacial surgeons had a multitude of approaches, which probably reflects their long and varied training in both medical and dental disciplines. These approaches inevitably started with simple conservative management, but also included various pharmacological approaches, bio-feedback, psycho-therapeutic techniques and the use of the pain clinic. The surgeons' consensus was that there are few indications for surgery in TMD and it was therefore extremely rare for them to perform any.

Biases also appear to occur in the surgeons' treatment decisions. The bias seems to be influenced by their experience and illustrates the possible subjectivity of experiential-based practice. A recurrently expressed example was the wish to do no harm with surgery, therefore again illustrating regret bias.[11] However, this approach to management also reflects the accepted maxim of providing conservative treatment, especially initially.

'I've seen disasters of people operating on TMJ. People with chronic pain come into hospital. Phoning in, coming in every week, being brought in and put into IMF just to quieten them down. Disasters. I've never had that disaster. I've never had a person like that in 25 years being treated conservatively' (OMFS 12).

The secondary care practitioners in general acknowledged the lack of evidence to base practice upon and reflected upon the possible misuse of the evidence as it stands. The concerns they expressed were the pursuit of possibly inappropriate irreversible treatments or non-evidence based treatments, thereby risking reinforcement of the patient's anxiety over their condition.

'There's very little good science in TMJ. There's a lot of witchcraft and there's a lot of opinion. And there are a lot of these evangelical factions propagating dubious scientific theories... The only thing that concerns me, as I say, is people that get irreversible interventions which ultimately are quite damaging.' (OMFS 6).

'If you embark upon a whole variety of different treatments none of which frankly have very much in the way of an evidence base to support their techniques, in my opinion you are reinforcing in the patient's mind that they do have a serious condition that is continuing to give them problems but that you are just unable to treat it.' (OMFS 9).

Practitioners' measure of clinical outcome

The lack of evidence to base practice upon within the literature has been accredited to the lack of a valid, reproducible outcome measure.[8-10] This lack of an outcome measure was evident in our data. The practitioners' measurement of success tended to be a subjective questioning of the patient. The outcome desired is best summarised by the following quotation: *'As long as they're comfortable, that's all I want really... I'm not after a silky smooth joint or anything'* (NGDP 14). Unfortunately this could lead to the possibility of explicit or implicit coercion of the patient to admit a decrease in pain and then discharge them with no further thought to their other potential complaints.

'[Success is] *a person who no longer needs to come and see me'* (OMFS 12).

'Realising that it's perhaps never going to be cured' (RD 8).

Practitioners could play on the 'white coat phenomenon' either consciously or subconsciously to try and discharge perceived recalcitrant patients. Given that practitioners have already been proven to be poor at ascertaining quality of life changes in patients with similar chronic conditions,[14] it would seem that this approach is problematic, and perhaps not in line with patients' needs.

SUMMARY

When considering TMD, it appears practitioners perceive it as a singular entity rather than a group of disorders with complex social implications. The lack of robust evidence currently available for the management of TMD, partly due to the lack of a valid and reproducible outcome measure, underpins an uncertainty in the diagnosis and management of TMD. In primary care the practitioners report a lack of education with respect to the condition and this, coupled with the lack of good quality evidence, leads to an uncertainty over diagnosis. The financial implications of TMD treatment in primary care further compound uncertainty and fear of misdiagnosis and appear to encourage referral to secondary care. Secondary care practitioners, in direct contrast, envisage that most of the initial management should have been initiated in primary care.

Within secondary care, the lack of evidence serves to create experiential-based practice, which the practitioners acknowledge. The secondary care practitioners seem more comfortable in their diagnosis and management of TMD compared to primary care practitioners due to their experience. However, the plethora of treatments prescribed would seem to suggest they too suffer from the same lack of evidence.

The dearth of high quality evidence, which has been reported elsewhere, is probably due in part to unreliable processes of determining success in the treatment of TMD. This subjectivity would seem to be central to encouraging the continued use of idiosyncratic experiential-based practice.

CONCLUSION

Our research identifies a series of problems resulting in difficulties with the management of TMD. Central to this is the lack of a valid reproducible outcome measure, which leads to difficulties in producing best quality evidence on which to base standardised practice. We feel it is important to stress that the real clinical difficulties and lack of consistency we have identified are a reflection of the lack of evidence, rather than the honest empathetic approach of the practitioners interviewed.

We can identify three areas that may require attention:

1. There is a need for better quality evidence on which to base management, including the development of a valid, reproducible patient-centred outcome measure
2. There appears to be a need for a primary care education initiative to help reduce practitioners' uncertainty. This could be based on diagnostic training, which has been shown to be successful previously
3. Dental contracting arrangements should allow appropriately trained primary care practitioners the ability, if they so wish, to provide initial management of TMD without financial penalty.

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8.5.2 Abstracts from scientific conferences

British Society of Dental Research meeting 2005

"Management is a Black Art" – Professional Opinions of Temporomandibular Disorders

J.Durham, J. Steele, R. Wassell, and C.Exley

Objective: To establish among professionals treating Temporomandibular Disorders (TMD) in the UK the rationale behind the use of different management methodologies.

Methods: This is a qualitative study using in-depth interviews to explore professionals' perceptions of TMD patients and treatments. The interview explored professional's perceptions of TMD patients and their problems, methods of management of TMD and professionals' definition of a successful treatment. A purposive sample (n= 20) of dental professionals was drawn from teaching institutions, district general hospitals and general dental practice in the U.K. Data collection and analysis occurred concurrently until saturation was reached. All data were audio-recorded and transcribed verbatim. Interviews were conducted by one researcher and analysed by two. The data were entered into a framework and both framework and constant comparative analysis were used to interpret it.

Results: The main emerging themes were: 1) there was an acknowledgement of the paucity of good quality evidence on which to base practice and definition of success; 2) practitioners recognised an element of distress inherent in TMD; 3) the management of TMD and some of these patients was difficult. With regard to treatment, initially a conservative, reversible approach was generally favoured. Success tended to be defined by the professional as patient satisfaction with symptomatic relief achieved and their ability to cope with the condition. Where it was not possible to achieve a successful outcome, some professionals suggested a more multi-disciplinary approach to patient care may be required.

Conclusion: This study highlights a number of key issues that should be raised in the professional forum for debate and points to the need for a national guideline on the management of TMD.

British Society of Dental Research and Scandinavian Division

meeting 2007

Comparison of Patient and Professional Perspectives on Temporomandibular Disorders(TMD)

J.Durham, C.Exley, R.W. Wassell, M.A. Moufti, and J.G. Steele

Objective: To establish whether professional views of TMD were reflected by people with TMD.

Methods: In depth interviews were used to explore both the professional and patient perceptions of TMD, including aspects of their experience of the condition. Two purposive samples (n= 20) were drawn. The first was from a range of dental professionals in primary and secondary care in the U.K. who managed TMD, encompassing all the specialties involved in its management. The second sample was from secondary care patients who had suffered from TMD and had received at least three months of treatment. Data from the professionals' sample informed the patients' topic guide. All data were audio-recorded and transcribed verbatim. The constant comparative method - whereby data collection and analysis occur concurrently until saturation is reached - was used for both samples. The two data sets were then compared.

Results: The main emergent themes were: 1) Pain experience; 2) Identity of complaint; 3) Psychological discomfort. Both patients and professionals identified chronic pain as the chief complaint associated with TMD, but when compared with patients, professionals consistently underestimated its psychosocial effects. Patients also reported that they rarely received a clear diagnosis within primary care, which correlated with a reported reluctance to make a diagnosis within primary care. The combination of pain and the lack of a diagnosis frequently resulted in significant anxiety over the source of their pain. For patients, the diagnosis and the reassurance given in secondary care were crucial to helping them cope with their symptoms.

Conclusion: This study highlights the importance of diagnosis and professional reassurance in the management of patients with TMD. It identifies a requirement for more appropriate training in diagnosis of TMD for both under and postgraduates.

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